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E-SOUVENIR
PROGRAMME



The 30th International Conference On Spina Bifida & Hydrocephalus

*Bridging The Healthcare And Prevention Gaps -
A Multidisciplinary Team Approach With The Community At Heart*

24 - 26
October 2024

AVANTÉ Hotel, Petaling Jaya, Selangor
Greater Kuala Lumpur, Malaysia

sbhconference2024.com

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Conference Information

OFFICIAL CONFERENCE VENUE

Level 1, AVANTÉ Hotel

1, Persiaran Bandar Utama, Bandar Utama,
47800 Petaling Jaya, Selangor, Malaysia

Waze: <https://waze.com/ul/hw283bks4n>

Google Maps: <https://maps.app.goo.gl/XxtverKx4W7iNqv37>

LECTURE HALLS AND LOCATION

Sapphire Ballroom - Level 1

Amber Room - Level G

Emerald Room - Level G

Garnet Room - Level G

Jasper Room - Level G

PARTICIPANT AND SPEAKER REGISTRATION COUNTER OPENING HOURS

24 October 2024, Thursday, 0700 – 1730 hrs

25 October 2024, Friday, 0700 – 1730 hrs

26 October 2024, Saturday, 0700 – 1600 hrs

SPEAKER READY ROOM

24 October 2024, Thursday, 0700 – 1730 hrs

25 October 2024, Friday, 0700 – 1730 hrs

26 October 2024, Saturday, 0700 – 1600 hrs

E-CERTIFICATE OF ATTENDANCE AND PRESENTATION, INVOICE AND RECEIPT

E-Certificate of Attendance and Presentation as well as Invoice and Receipt will be available on your delegate dashboard for 1 month post conference. Please download the documents needed **before 27 November 2024**.

PARKING

Flat Rate is RM7.00 nett per day.

Please bring along your TnG Card or Credit/Debit Card for validation at the conference area.

SURAU

Level G, AVANTÉ Hotel

LANYARD

Only those with lanyards and name tags will be allowed into the conference area.

CPD POINTS

MMA CPD Points: 20 MMA CPD points will be awarded to all delegates who attend the conference. The organiser will submit the attendance list to the respective bodies for CPD accreditation 1 week post conference.

Medical Specialist CPD: 20 CPD points will be awarded to all Malaysian Specialists under the Medical Specialist CPD system who attend the conference. All specialists are to search by the Event ID: 30965 on the Medical Specialist CPD system to claim the CPD points.

MyCPD CPD Points: The following list of healthcare professionals have been approved for CPD Points by MyCPD.

- Clinical Psychologist
- Psychologist (Counselling)
- Health Education Officer
- Occupational Therapist
- Physiotherapist
- Psychologist (General)
- Assistant Medical Officer
- Dietitian
- Nutritionist
- Speech-Language Therapist
- Audiologist
- Clinical Scientist (Medical Geneticist)
- Medical Social Officer
- Registered Medical Practitioner

As notified by MyCPD, their system has just started operating, a reminder to the healthcare professional attendees who use MyCPD system to follow the standard MyCPD procedure.

NEAREST MOSQUE FOR FRIDAY PRAYERS

- **Surau Al-Syakirin, Bandar Utama** (3-mins Driving Distance, 16-mins Walking Distance)
- **Al-Mujahideen Mosque** (7-mins Driving Distance, 21-mins Walking Distance)



The 30th
International Conference On
Spina Bifida & Hydrocephalus

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Conference Secretariat



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Welcome Message

We are thrilled to welcome you to the 30th International Conference on Spina Bifida and Hydrocephalus, held right here at AVANTÉ Hotel, Petaling Jaya, Selangor. This event marks a significant gathering of individuals, families, healthcare professionals, policymakers, and researchers from around the world, all here to discuss the latest advancements in Spina Bifida and Hydrocephalus (SBH).

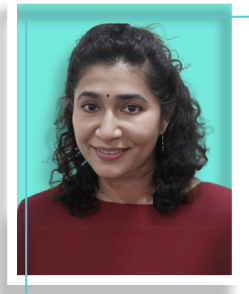
As a highlight of the event, we invite you to join us for our fundraising Gala Dinner, 'An Evening of Stars and Strides', where we will celebrate the achievements and resilience of individuals living with SBH. The evening will feature cultural performances, inspiring speeches, and an opportunity to recognise outstanding contributions from our SBH community.

This conference coincides with the World Spina Bifida and Hydrocephalus Day on 25 October 2024. Together we shall commemorate the annual international day dedicated to fostering support for individuals impacted by this condition whilst celebrating their contribution and achievements in all areas of life.

The local organisers of this event, the Spina Bifida and Hydrocephalus Association of Malaysia (SIBIAM) is an association that has tirelessly served the SBH community in Malaysia for more than 17 years. Over the years SIBIAM has formed strategic partnerships with the Rotary Club Damansara and the District Action Group for Spina Bifida and Hydrocephalus (DASH) a special initiative within the Rotary network to carry out its activities.

Therefore, together, we look forward to providing you with an ambitious program as part of this 30th anniversary International Conference on Spina Bifida and Hydrocephalus in the beautiful city of Petaling Jaya, Selangor taking place from 24 to 26 October 2024.

We are so glad to have you here with us, and we hope you have an incredible and memorable time at this conference.



Prof Dr Amaramalar Selvi Naicker
*President of SIBIAM
& Chair of National Organising Committee for
the 30th ICSBH 2024*



Dr Sylvia Roozen
*Secretary General of IFSBH
& Chair of International Scientific Committee
for the 30th ICSBH 2024*

About SIBIAM

Since 2007, the Spina Bifida & Hydrocephalus Association of Malaysia (SIBIAM) has empowered individuals with Spina Bifida and Hydrocephalus (SBH) and their families. This non-profit organisation brings together SBH individuals, families, healthcare professionals, Rotarians, and volunteers to champion the SBH community.

SIBIAM's objectives are to increase awareness about Spina Bifida and its related complications affecting lives of persons with Spina Bifida and to provide assistance in areas of healthcare, medical & rehabilitation devices, education and support to ensure equal access to education and vocation and finally to encourage social integration and the will to stay strong and live a healthy, active and independent life as members of the community through planned projects, national and international events, self-help programmes and advocacy.

SIBIAM's motto is "ALWAYS BY YOUR SIDE". The Willing Spirit represents the passion of the association to motivate and encourage SBH persons to be the best version of themselves.

Mission: To assist SBH community through direct support to members, education and awareness as well as advocacy.

Our vision is to become a one-stop solutions provider for SBH persons, family members and friends, through which we can provide an avenue for open communications among members. The organisation also serves as a platform for patients and their loved ones to obtain and share relevant information on disease management. Ultimately, our goal is to organise and support an increasing number of activities related to Spina Bifida and Hydrocephalus.

Committee Member List Of 2023-2025

President	Prof Dr Amaramalar Selvi Naicker	
Vice President	Ir. Dr Kribanandan Gurusamy Naidu	
Treasurer	Mr Nazri Mohamed Rasdi	
Assistant Treasurer	Mr Edward Poh Seng Aik	
Secretary	Dr Chan Yean Koon	
Assistant Secretary	Mr Roszaidi Ramlee	
Committee Members	<ul style="list-style-type: none"> • Mr Francis Arulanandam • Mr Harmesh Singh • Mr Khairul Aizat • Ms Nur Khalilatul Amla Kamal Subki 	
Internal Auditor	Mr Steven Gan Eng Huat	

About IFSBH

The International Federation for Spina Bifida and Hydrocephalus (IF) was founded by people with Spina Bifida and Hydrocephalus (SBH) and their families in 1979. Over the years, it has grown from a voluntary association into a professional disabled people's organisation (DPO) with global coverage, democratic structure and transparent and accountable processes.

A BETTER LIFE FOR EVERYONE

IFSBH highest value is the promotion and protection of the human rights of people with Spina Bifida and Hydrocephalus by the UN Convention on the Rights of Persons with Disabilities.

The majority of IF member organisations are led and governed by adults with SBH or parents of children with SBH. Children are active participants in IFSBH members' activities: they are involved in child-led activities, training workshops on independence and holiday camps.

Nowadays, many young people with SBH have taken over the leadership of their organisations. In most cases, IF members choose close cooperation with medical and education professionals and researchers, given the importance of these professions to children and adults with SBH for their survival and development.

MISSION AND GOALS

The mission of the International Federation for Spina Bifida and Hydrocephalus is:

- to improve the quality of life of people with Spina Bifida and Hydrocephalus and their families
- to reduce the prevalence of neural tube defects and Hydrocephalus by primary prevention

by raising awareness, and through political advocacy, research, community building and human rights education.



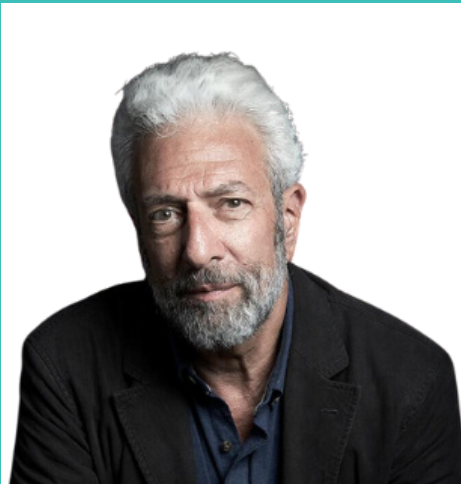
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the European Union

Disclaimer: Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Commission. Neither the European Union nor the granting authority can be held responsible for them.

30th ICSBH 2024 Committee

National Organising Committee Chair	Prof Dr Amaramalar Selvi Naicker President of Spina Bifida and Hydrocephalus Association of Malaysia
National Organising Committee Co-Chair	Ir. Dr Kribanandan Gurusamy Naidu Chairperson of the District Action Group for Spina Bifida and Hydrocephalus (DASH)
International Scientific Committee Chair	Dr Sylvia Roozen Secretary General of IFSBH, Brussels, Belgium
National Scientific Committee Chair	Prof Dr Rashidah Ismail @ Ohnmar Htwe
National Scientific Committee Co-Chair	Dr Chern Phei Ming
International Scientific Committee	Prof Dr Richard Finnell, USA Prof Dr Jacques Scheres, the Netherlands Dr Quentin Johnson, Canada Dr Eva Bermejo Sanchez, Spain
National Scientific Committee	Assoc Prof Dr Muhammad Kamal Muhammad Abdul Jamil Dr Azizi Abu Bakar Dr Chan Yean Koon Dr Lim Li Yi Dr Malini Mahalingam Dr Nurulhuda Zakari@Zakaria Dr Ooi Ai Lee Dr Sharon Anne Khor Dr Srihari Singaravel Dr Tan Lay Tin Dr Tan Yew Wei Dr Teh Chee Ming Dr Yusma Asni Yusmido Ms Chua Siew Chien Mr Fann Lim Ms Farizan Abdul Majid Ms Nor Azizah Mohamad Ms Norazah Haron Ms Nur Khalilatul Amla Kamal Subki
SBH Family Committee	Dr Aiza Shafrina Othman Dr Yang Mee Eng Mr Harmesh Singh Mr Nazri Mohamed Rasdi Mr Yee Wing Wei Ms Beh Cheah Cheah Ms Fatin Fatinah Shamshul Bahrin Ms K. Aveena Devi Ms Nur Aini Salamat Ms Siti Zulaikha Mohamad Noor Ms Su Xiao Vin
Rotarians / DASH Committee	Past President, Ir. Dr Kribanandan Gurusamy Naidu (Rotary Club Damansara) Past District Governor, Leslie Salehuddin (Rotary Club Gombak) Assistant Governor, Kovind M Jaganathan (Rotary Club Senawang)
Social Programme Committee	Dr Elyana Jalil Dr Chan Yean Koon Dr Punithamalar Sundrasegaran Dr Wan Juhaini Paizi@Fauzi
Sponsorship Committee	Dr Chua Li-Shun
Treasurer	Dr Chan Yean Koon Mr Nazri Mohamed Rasdi
Secretariat	Medical Conference Partners Mahesvari Varatharaj

Keynote Speaker 1



PROF DR RICHARD FINNELL

Distinguished Professor of
Paediatric Genetics,
Baylor College of Medicine,
USA

Keynote Topic

The Biology Of Neural Tube Defects: From Prevention Efforts To Stem Cell Therapeutics

Short Biography

Professor Richard H. Finnell holds the William T. Butler, M.D. Distinguished Chair in the Center for Precision Environmental Health at Baylor College of Medicine. A pediatric geneticist, Dr. Finnell has academic appointments in the Department of Molecular and Cell Biology, the Department of Molecular and Human Genetics, and in the Department of Medicine. During his 44+-year career, he has authored over 400 peer-reviewed publications in journals such as Science, Nature Genetics, Nature Cell Biology, PNAS and Developmental Cell. The current focus of the laboratory is to utilize gene-editing approaches in stem cells to treat complex congenital malformations and unique genetic defects in the one carbon metabolic pathway. His ongoing research efforts are funded by multiple grants from the US National Institutes of Health.

Keynote Topic

**Prevention of Neural Tube Defects:
Leaving No One Behind**

Short Biography

Dr Juliawati Untoro is a Scientist at the Multisectoral Action in Food Systems Unit of the Department of Nutrition and Food Safety, WHO Headquarters in Geneva, Switzerland. She provides technical support to regions and countries, fostering partnerships and network, and building capacity to design and implement policies that promote healthy food environments, with a particular focus on food fortification and the elimination of trans fats.

With over 25 years of experience in international development, Dr Untoro has been a strong advocate for advancing public health nutrition programs, particularly in low-and middle-income countries. She has worked with numerous multilateral organizations, including as WHO, UNICEF, the World Bank, Nutrition International, and the SEAMEO Regional Center for Food and Nutrition at the University of Indonesia. Her career has spanned the globe, with postings in Indonesia, Canada, the USA, Kenya, the Philippines, and now Switzerland.

Dr Untoro holds a PhD in Human Nutrition from Wageningen University, the Netherlands, and has authored several articles in international peer-reviewed journals.

Keynote Speaker 2



DR JULIAWATI UNTORO

Scientist at the Multisectoral
Action in Food Systems
Unit of the Department of
Nutrition and Food Safety,
WHO Headquarters in Geneva,
Switzerland

Faculty



Agnieszka Pastuszka
*Prof Dr, Fetal Surgeon,
Paediatric Surgeon &
Paediatric Urologist*
Poland



Ahmad Zaidin Othman
*Mr, Senior Case
Manager Rehabilitation and
Quality Monitoring of PERKESO*
Malaysia



Amaramalar Selvi Naicker
*Prof Dr, President of
SIBIAM
& Chair of National Organising
Committee of ICSBH 2024*
Malaysia



Amar-Singh HSS
*Dato' Dr, Paediatrician &
Child-Disability Activist*
Malaysia



Amita Vivehanantham
Dr, Neonatologist
Malaysia



Anastasia Smith
*Ms, Coordinator,
Global Alliance for the
Prevention of Spina Bifida F
& Clinical Research Manager*
USA



Andrea Koh
Ms, Sexologist & Counsellor
Malaysia



Andrej Drdul
*Mr, Co-Founder And Board
Member Of The Slovak
Association for Spina Bifida and/
or Hydrocephalus & Special
Teacher*
Slovakia



Arvind Betigeri
*Dr, Regional Food Fortification
Advisor of WFP*
Thailand



Ayoub Al-Jawaldeh
*Dr, Regional Advisor in Nutrition
& Head of Nutrition Unit,
WHO-EMRO*
Egypt



Ayu Primarini
*Mdm, Advocacy and Public
Relations in Disability Care*
Indonesia



Azizi Abu Bakar
Dr, Neurosurgeon
Malaysia



Cato Lie

*Mr, Norwegian Association
(Ryggmargsbrokk-og
hydrocephalusforeningen)
Norway*



Chan Yeap Koon

*Dr, Rehabilitation Physician
Malaysia*



Cheah Phaik Lin Jeannie

*Ms, Clinical Psychologist
Malaysia*



Chern Phei Ming

*Dr, Head of Paediatric
Rehabilitation Unit & Clinical
Research Centre, HRC
Malaysia*



Christian Radmayr

*Prof Dr, Paediatric Urologist
Austria*



Christina Anastas

*Ms, Senior Physiotherapist
(Spinal Rehabilitation)
Australia*



Christine Kuca-Thompson

*Ms
Australia*



Chua Li-Shun

*Dr, Rehabilitation Physician
Malaysia*



Chua Siew Chien

*Ms, Clinical Nurse Educator
Malaysia*



Cut Hafifah

*Dr, Paediatrician & Consultant of
Paediatric Nutrition and
Metabolic Disease
Indonesia*



Daniel Lee

*Mr, Motivational Speaker
Malaysia*



Dharmendra Ganesan

*Prof Dr, Paediatric Neurosurgeon
Malaysia*

Faculty



Eduardo Tizzano
*Prof Dr, Paediatrician
& Medical Geneticist*
Spain



Edward Chan
Dr, Clinical Director of WellLab
Malaysia



Elyana Jalil
Dr, Rehabilitation Physician
Malaysia



Erin McNamara
Dr, Paediatric Urologist
USA



Fann Lim
Mr, Certified Prosthetist Orthotist
Malaysia



Faridah Omar
Mdm, Physiotherapist
Malaysia



Farizan Abdul Majid
Ms, Nurse
Malaysia



Fong Choong Yi
Prof Dr, Paediatric Neurologist
Malaysia



Gayathri Mariappa
*Dr, Obstetrician, Gynaecologist &
Maternal Fetal Medicine Specialist*
Malaysia



Glenn Gardener
*Dr, Maternal Fetal
Medicine Specialist*
Australia



Goh Shi Ying
Ms, Occupational Therapist
Malaysia



Hatim Thaker
*Dr, Paediatric Urologist
& Surgeon Scientist*
USA



Hatta Sidi

*Prof Dr, Psychiatrist
Malaysia*



Hazati Raya

*Ms, Paediatric Specialist
Continence Nurse
Malaysia*



Jeffrey Blount

*Prof Dr, Paediatric Neurosurgeon
USA*



Julian Sander

*Mr, Regional Business Manager of
Stern Ingredients Asia-Pacific
Singapore*



Juliawati Untoro

*Dr, Scientist at the Multisectoral
Action in Food Systems Unit of
the Department of Nutrition and
Food Safety, WHO Headquarters
in Geneva
Switzerland*



Kateryna Shcherbyna

*Ms, Chair of IFSBH International
Youth Group with SBH, Brussels,
Belgium*



K. Aveena Devi

*Ms, Mixed Media Artist, Author &
Motivational Speaker
Malaysia*



Kerrie Duff

*Mdm, Paralympian and Disability
Consultant
Australia*



Khursheed Durrani

*Mr, Assistant General Manager of
Hexagon Nutrition Ltd
India*



Khushbu Ganatra

*Ms, Co-Founder and Director of
Walk n Wheels Foundation
India*



**Kribanandan
Gurusamy Naidu**

*Ir. Dr, Vice President of SIBIAM,
Chairperson of Rotary DASH &
Co-Chair of National Organising
Committee of ICSBH 2024
Malaysia*



Krishnaveni P Krishnan

*Mdm, Parent of SBH Individual
Malaysia*

Faculty



Kristin Sundell
*Ms, Senior Advocacy Specialist
of GAIN
USA*



Lara Arosemena
*Ms, Founder and President of
Zero Limite Espina Bifida Panama
Panama*



Laurence Leser
*Ms, Executive Director of Associ-
ation de spina-bifida et d'hy-
drocéphalie du Québec
Canada*



Lim Li Yi
*Dr, Urologist
Malaysia*



Lim Yee Jin
*Ms, Paralympic Chess Player
Malaysia*



Liv Tørring
*Ms, Managing Director of
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Low Peh Hueh
*Dr, Neurosurgeon
Malaysia*



Ludivicus Omollo
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Maahi Rudawat
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Majdah Mohamed
*Dr, Senior Principal Assistant
Director of Family Health
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Malini Mahalingam
*Dr, Paediatric Neurologist
Malaysia*



Margo Whiteford
*Dr, Consultant Clinical Geneticist
Scotland*



Maria Lourdes Bolong
*Dr, Treasurer of Spina Bifida
Support Group Foundation, Inc.*
Philippines



Matthias Axt
Dr, Orthopaedic Surgeon
Australia



Miza Marsya Roslan
Ms, UNICEF Young Leader & PWD
Advocate
Malaysia



**Mohamad Firdaus
Mohd Jafri**
Mr, SBH Individuals
Malaysia



Mohammad Aminuddin
Mr, Occupational Therapist
Malaysia



**Muhammad Kamal
Muhammad Abdul Jamil**
*Assoc Prof Dr, Orthopaedic
Surgeon*
Malaysia



Mustaffa Sultan
Mr, Physiotherapist
Malaysia



Nebiyat Tesfaye
*Dr, SBH Technical Director of
ReachAnother Foundation*
Ethiopia



Ng Swee Guan
Mr, Senior Education Audiologist
Malaysia



Norazah Haron
Ms, Senior Physiotherapist
Malaysia



Nor Azidah Mohamad
Ms, Senior Physiotherapist
Malaysia



**Nor Khairunnisa
Mohamad**
Mdm, Occupational Therapist
Malaysia



Norsyafiqah Samsuri
Ms, Rehab Assistant Manager
Malaysia



**Nur Khalilatul Amla
Kamal Subki**
Ms, Occupational Therapist
Malaysia



**Nur Syafiqah Mustaffa
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Ms, Occupational Therapist
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Faculty



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Ooi Ai Lee
Dr, Rehabilitation Physician
Malaysia



Poongkodi Nagappan
Dr, Urologist
Malaysia



Punithamalar Sundrasegaran
Dr, Rehabilitation Physician
Malaysia



Quentin Johnson
Dr, Senior Advisor Food Fortification
Canada



Raja Nurul Faizah Raja Hamzah
Ms, Paediatric Specialist Contenance Nurse
Malaysia



Rashidah Ismail @ Ohnmar Htwe
Prof Dr, Rehabilitation Physician
Malaysia



Richard Finnell
Prof Dr, Paediatric Geneticist
USA



Rusidah Selamat
Ms, Director of Nutrition Division, MOH
Malaysia



Ruth Nalugya
Ms, Executive Director of Spina Bifida and Hydrocephalus Association of Uganda
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Santosh Karmarkar
Dr, Paediatric Surgeon
India



Sharon Anne Khor
Dr, Rehabilitation Physician
Malaysia



Sharon Bustrak
Ms, Technical Advisor of FFI
USA



Siti Zulaikha Mohamad Noor
Ms, Occupational Therapist
Malaysia



Sivanesan Govindasamy
Dr, Deputy President of Special Olympics Malaysia
Malaysia



Sneha Sawant
Ms, Chief Executive Officer of Spina Bifida Foundation India
India

Faculty



Srihari Singaravel
Dr, Paediatric Urologist
Malaysia



Su Xiao Vin
Ms, Pharmacist
Malaysia



Syed Abd Rahman Syed Hassan
Hj, Ambassador
DiveHeart Malaysia
Malaysia



Sylvia Roozen
Dr, Secretary General of IFSBH
Brussels, Belgium



Tan Chai Eng
Assoc Prof Dr, Family Medicine
Consultant
Malaysia



Tan Lay Tin
Dr, Paediatrician
Malaysia



Tan Lee Na
Dr, Obstetrician, Gynaecologist &
Maternal Fetal Medicine Specialist
Malaysia



Tan Yew Wei
Dr, Paediatric Surgeon
Malaysia



Teh Chee Ming
Dr, Paediatric Neurologist
Malaysia



Teo Shu Ching
Dr, Paediatric Anaesthesiologist
Malaysia



Venkat Sripathi
Prof Dr, Paediatric Urologist
India



Victoria Sandoval Cáceres De Lara
Mdm, President of IFSBH
Guatemala



Wan Juhaini Paizi@Fauzi
Dr, Rehabilitation Physician
Malaysia



Yee Wing Wei
Mr, Physiotherapist
Malaysia



Yusma Asni Yusmido
Dr, Rehabilitation Physician
Malaysia



Join us for an engaging workshop on
'SBH Prevention and Human Rights: The
Power of Advocacy and Alliance Building'
Friday 25 October 15.30 - 17.00

Check out the Food Fortification Advocacy Toolkit
Implementing the World Health Assembly (WHA)
Resolution for Food Fortification

Accelerating Progress on Food Fortification at
the 2025 Nutrition for Growth (N4G) Summit



Visit the toolkit webpage
for advocacy briefs, a
communication guide,
and other resources.

Stop by our
booth in the
exhibit area for
more resources
and support!

Here's what you can do to advocate for stronger food fortification programmes in your country:

- 1.** Reach out to others to coordinate efforts. Advocacy is more impactful when diverse stakeholders act together. See the toolkit for links to organizations you might try to connect with.
- 2.** Work with other national stakeholders to identify an "ask" outlining how food fortification could be strengthened in your country. Information about your national food fortification program and standards can be found at www.fortificationdata.org.
- 3.** Together with your advocacy partners, seek an in-person meeting with the Minister of Health or his/her staff to discuss your "ask."
- 4.** Ask the Minister of Health to lead national implementation of the World Health Assembly resolution by creating a plan to strengthen national food fortification programs and including food fortification in the national N4G commitment.
- 5.** Keep following up! Advocacy is most effective when it becomes an ongoing (friendly) dialogue. One-off meetings are rarely effective.

Have questions or suggestions? Contact us at futurefortified@gainhealth.org.

 **The 30th**
International Conference On
Spina Bifida & Hydrocephalus

Opening Ceremony

Date: 24 October 2024

Time: 1600 - 1730 hrs

Venue: Sapphire Ballroom, AVANTÉ Hotel, Petaling Jaya, Selangor

1630 - 1635 hrs

Entrance of Guest of Honour

Datuk Dr Muhammad Radzi bin Abu Hassan
Director General of Health, Ministry of Health Malaysia

1635 - 1645 hrs

Negaraku

Welcome Note by Emcee
Prayer Recital

1645 - 1650 hrs

Welcome Address by

Prof Dr Amaramalar Selvi Naicker
President of Spina Bifida and Hydrocephalus Association of Malaysia (SIBIAM) &
Chair of National Organising Committee for the 30th International Conference on
Spina Bifida & Hydrocephalus 2024

1650 - 1655 hrs

Welcome Message by

Dr Sylvia Roozen
Secretary General of the International Federation for
Spina Bifida and Hydrocephalus (IFSBH) &
Chair of International Scientific Committee for the 30th International Conference on
Spina Bifida & Hydrocephalus 2024

1655 - 1700 hrs

Opening Speech by

Datuk Dr Muhammad Radzi bin Abu Hassan
Director General of Health, Ministry of Health Malaysia

1700 - 1710 hrs


Officiating Ceremony

1710 - 1730 hrs

Departure of Guest of Honour
End of Opening Ceremony

Programme Overview

Day 1 - 24 October 2024 (Thursday)

Time (hrs)	Sapphire Ballroom	Time (hrs)	Amber Room
0700 - 1730	Registration	0700 - 1730	Registration
0815 - 0830	Welcome Remarks	0815 - 1015	Join Us in Sapphire Ballroom
0830 - 0945	Country Updates		
0945 - 1015	Sponsored Symposium by WellLab 		
1015 - 1045	Tea Break	1015 - 1045	Tea Break
1045 - 1115	Keynote 1: The Biology of Neural Tube Defects: From Prevention Efforts to Stem Cell Therapeutics	1045 - 1300	SBH Community Networking Session Getting to Know Malaysia and Each Other
1115 - 1145	Plenary 1: A Practical Approach to the Genetics of Neural Tube Defects		
1145 - 1205	Plenary 2: Landmarks and the Future of Spina Bifida Prevention		
1205 - 1225	Plenary 3: Building a Multidisciplinary Team and Why This Matters		
1225 - 1300	Keynote 2: Prevention of Neural Tube Defects: Leaving No One Behind		
1300 - 1400	Lunch, Exhibit Visit & Networking	1300 - 1400	Lunch, Exhibit Visit & Networking
1400 - 1430	Roundtable Discussion 1: Facing a Pregnancy with a Neural Tube Defect: A Cascade of Communications and Shared Decision Making	1400 - 1500	Workshop 1: Intellectual Discussion On SB: Community & Healthcare Awareness - Are We There Yet?
1430 - 1450	Antenatal Screening & Care in Fetal NTD through Delivery		
1450 - 1510	Pre Pregnancy Care and Antenatal Journey for Women with Spina Bifida		
1510 - 1530	The State of Fetal Spina Bifida Surgery: Today and Tomorrow	1500 - 1600	Workshop 2: Hospital Visits - The Knowns and Unknowns
1530 - 1550	The Impact of Fetal Spina Bifida Surgery on Hydrocephalus Management and Care		
1600 - 1730	Opening Ceremony	1600 - 1730	Join Us in Sapphire Ballroom
1730	End of Day 1		

Programme Overview


Day 2 - 25 October 2024 (Friday)

Time (hrs)	Sapphire Ballroom	Time (hrs)	Emerald Room	Time (hrs)	Garnet Room	Jasper Room	Amber Room
0700 - 1730	Registration	0700 - 1730	Registration	0700 - 1730	Registration		
0745 - 0830	Best Free Paper Oral Presentation Award (Judging Session)	0730 - 0830	Free Paper Oral Presentation 2	0730 - 0830	Free Paper Oral Presentation 3	Free Paper Oral Presentation 4	<p>Larger Scale Food Fortification Workshop (LSFF): Importance of Measures to Prevent Micronutrient Deficiencies'</p> <p><i>By Invitation Only</i></p>
0830 - 0900	Plenary 4: Ethical Issues: A Global Perspective	0830 - 1000	Join Us in Sapphire Ballroom	0830 - 1000	Join Us in Sapphire Ballroom		
0900 - 1000	Plenary 5: Advocacy for Disability Inclusion						
1000 - 1030	Tea Break	1000 - 1030	Tea Break	1000 - 1030	Tea Break		
1030 - 1050	Spinal Cord Release: Sciences Vs Reality	1030 - 1110	<p>Roundtable Discussion 2: Transition from Paediatric to Adulthood: When the Voice of the Patient is Becoming More Important than the Voice of the Parent</p>	1030 - 1230	Workshop 3: Schooling & Education for Children with Special Needs	Workshop 4: Community Integration: Recreational Activities for Persons With Disabilities	
1050 - 1110	Neurosurgical Perspective in Spina Bifida & Management of Hydrocephalus						
1110 - 1130	Early Bladder Management in the Neurogenic Bladder - How to Evaluate and How to Manage						
1130 - 1150	Is There a Role of Video Urodynamics Study in Spina Bifida						
1150 - 1210	Engineered/Fusion Toxins for Treatment of Neurogenic Bladder Dysfunction	1110 - 1240	<p>Youth Forum: Stronger Together - Youth Sharing Experiences about Living with SBH in Terms of Mental Health</p>				
1210 - 1240	Innovative Multidisciplinary Approach to Developing Clinical Practice Guidelines for Neurogenic Bladder Management in Children and Adolescents: A Collaborative Endeavor						
1240 - 1430	Lunch, Friday Prayer, Exhibit Visit & Networking	1240 - 1430	Lunch, Friday Prayer, Exhibit Visit & Networking	1230 - 1430	Lunch, Friday Prayer, Exhibit Visit & Networking		

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Programme Overview

Day 2 - 25 October 2024 (Friday)

Time (hrs)	Sapphire Ballroom	Time (hrs)	Emerald Room	Time (hrs)	Garnet Room	Jasper Room	Amber Room
1430 - 1500	POO Power: Developing a Logical Framework and Network for Managing Neurogenic Bowel	1430 - 1700	Workshop 5: Urology				Large Scale Food Fortification Workshop (LSFF): Importance of Measures to Prevent Micronutrient Deficiencies' <i>By Invitation Only</i>
		1430 - 1450	Successful Management of Incontinence				
1500 - 1530	Bridging the Gap Collaborative Care from Hospital to Home for SBH Patients	1450 - 1510	Robotic Surgery in Patients with Spina Bifida	1500 - 1700	Workshop 6: Work And Careers for Persons with Spina Bifida & Hydrocephalus	Workshop 7: Becoming an Advocate in Your City	
1530 - 1700	GAIN Workshop 8 	1510 - 1700	Workshop/ Case Discussion on Urodynamic Study				
1700 - 1730	Best Poster Award Judging Session						
1730	End of Day 2						

Programme Overview

Day 3 - 26 October 2024 (Saturday)

Time (hrs)	Sapphire Ballroom	Time (hrs)	Amber Room	Emerald Room
0700 - 1600	Registration	0700 - 1600	Registration	
0730 - 0830	Free Paper Oral Presentation 5	0730 - 0830	Free Paper Oral Presentation 6	Free Paper Oral Presentation 7
0830 - 0900	Plenary 6: Trial and Tribulations of Transition Care	0830 - 1030	Workshop 9 (Gait Assessment and Orthoses): Understanding the Biomechanics of Different AFOS and How They Affect Gait	Workshop 10 (Occupational Therapy): Getting Independence
0900 - 0930	Plenary 7: Quality of Life and Ageing with Spina Bifida			
0930 - 0950	Common Musculoskeletal Problems in Spina Bifida - Rehabilitation Approach			
0950 - 1010	Orthopaedic Management in Spina Bifida			
1010 - 1030	Bone Health and Vitamin D Deficiency in Spina Bifida			
1030 - 1100	Tea Break	1030 - 1100	Tea Break	
1100 - 1120	Nutritional Challenges in Paediatric Patients with Spina Bifida	1100 - 1300	Workshop 11 (Neurogenic Bowel and Bladder): Keeping Continent CIC and Bowel Care	Workshop 12 (Physiotherapy): Physiotherapy in Spina Bifida: Maximising Potential in the Growing Child
1120 - 1150	Forum: Advancing Understanding on Urological and Mental Health Needs in an Ageing SBH Community			
1150 - 1310	Workshop 13: Prenatal Surgery for Fetal Spina Bifida: The Journey from Diagnosis			
1310 - 1400	Lunch, Exhibit Visit & Networking	1310 - 1400	Lunch, Exhibit Visit & Networking	
1400 - 1600	Workshop 14: Sexual Health in SBH	1400 - 1630	Join Us in Sapphire Ballroom	
1600 - 1630	Closing Ceremony			
1900 Onwards	An Evening of Stars & Strides Fundraising Gala Dinner			

Day 1 : Detailed Programme

24 October 2024 (Thursday)

Time (hrs)	Sapphire Ballroom	Time (hrs)	Amber Room		
0700 - 1730	Registration	0700 - 1730	Registration		
0815 - 0830	Welcome Remarks Prof Dr Amaramalar Selvi Naicker, Malaysia <i>President of SIBIAM</i> Mdm Victoria Sandoval Cáceres De Lara, Guatemala <i>President of IFSBH</i>	0815 - 1015	Join Us in Sapphire Ballroom		
0830 - 0945	Country Updates <i>Chairperson:</i> Ir. Dr Kribanandan Gurusamy Naidu, Malaysia				
0830 - 0835	Opening Remark Ir. Dr Kribanandan Gurusamy Naidu, Malaysia				
0835 - 0840	Accessibility to Prevention and Care in Latin America Mdm Victoria Sandoval Cáceres De Lara, Guatemala				
0840 - 0845	Up Date on Guatemala SB Situation Mdm Victoria Sandoval Cáceres De Lara, Guatemala				
0845 - 0850	Country Update: Empowering Lives Through Spina Bifida and Hydrocephalus Initiatives in Uganda Ms Ruth Nalugya, Uganda				
0850 - 0855	Understanding and Welcoming People With Spina Bifida and Hydrocephalus Ms Laurence Leser, Canada				
0855 - 0900	Country Update Norwegian Association for Spina Bifida and Hydrocephalus Ms Liv Tørring, Norway				
0900 - 0905	Country Update: Scotland Dr Margo Whiteford, Scotland				
0905 - 0910	Camps for Children and Young People with Disability Mr Andrej Drdul, Slovakia				
0910 - 0915	Work and Activities of the Foundation in India Ms Sneha Sawant, India				
0915 - 0920	Country Update - Spina Bifida and Hydrocephalus Association of Malaysia (SIBIAM) Dr Chua Li-Shun, Malaysia				
0920 - 0925	Spina Bifida in Indonesia: Challenges, Needs and Sustainability Mdm Ayu Primarini, Indonesia				
0925 - 0930	Australia: Where Are We Now? Mdm Kerrie Duff, Australia Ms Christine Kuca-Thompson, Australia				
0930 - 0935	Out-of-pocket Expenditures of Spina Bifida and Congenital Hydrocephalus Patients Enrolled for Inpatient Treatment and Follow-up at St. Peter Specialized Hospital and Zewditu Memorial Hospital, Addis Ababa Ethiopia Dr Nebiyat Tesfaye, Ethiopia				
0935 - 0940	A 25th Anniversary of Empowering Filipinos with Spina Bifida Dr Maria Lourdes Bolong, Philippines				
0945 - 1015	Sponsored Symposium by WellLab				
	How to Test for Genetic Vulnerability for SBH/ NTD Child & Mother to Customise Supplements Solutions Dr Edward Chan, Malaysia				
1015 - 1045	Tea Break				

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Time (hrs)	Sapphire Ballroom	Time (hrs)	Amber Room
	<p><i>Chairperson:</i> <i>Dr Sylvia Roozen, Brussels, Belgium</i></p>		
1045 - 1115	<p>Keynote 1: The Biology of Neural Tube Defects: From Prevention Efforts to Stem Cell Therapeutics <i>Prof Dr Richard Finnell, USA</i></p>	1045 - 1300	<p>SBH Community Networking Session Getting to Know Malaysia and Each Other</p> <p><i>Facilitators:</i> <i>Dr Chan Yean Koon, Malaysia</i> <i>Dr Elyana Jalil, Malaysia</i> <i>Dr Punithamalar Sundrasegaran, Malaysia</i> <i>Dr Wan Juhaini Paizi@Fauzi, Malaysia</i></p>
1115 - 1145	<p>Plenary 1: A Practical Approach to the Genetics of Neural Tube Defects <i>Prof Dr Eduardo Tizzano, Spain</i></p>		
1145 - 1205	<p>Plenary 2: Landmarks and the Future of Spina Bifida Prevention <i>Ms Sneha Sawant, India</i></p>		
1205 - 1225	<p>Plenary 3: Building a Multidisciplinary Team and Why This Matters <i>Dr Erin McNamara, USA</i></p>		
1225 - 1300	<p>Keynote 2: Prevention of Neural Tube Defects: Leaving No One Behind <i>Dr Juliawati Untoro, Switzerland</i></p>		
1300 - 1400	Lunch, Exhibit Visit & Networking	1300 - 1400	Lunch, Exhibit Visit & Networking
1400 - 1430	<p>Roundtable Discussion 1: Facing a Pregnancy with a Neural Tube Defect: A Cascade of Communications and Shared Decision Making <i>Moderator:</i> <i>Prof Dr Eduardo Tizzano, Spain</i></p> <p><i>Panellists:</i> <i>Prof Dr Agnieszka Pastuszka, Poland</i> <i>Dr Nebiyat Tesfaye, Ethiopia</i> <i>Mr Andrej Drdul, Slovakia</i> <i>Dr Gayathri Mariappa, Malaysia</i></p>	1400 - 1500	<p>Workshop 1: Intellectual Discussion On SB: Community & Healthcare Awareness - Are We There Yet? <i>Moderator:</i> <i>Dr Elyana Jalil, Malaysia</i></p> <p><i>Speakers:</i> <i>Ms K. Aveena Devi, Malaysia</i> <i>Dr Punithamalar Sundrasegaran, Malaysia</i> <i>Ms Su Xiao Vin, Malaysia</i> <i>Dr Wan Juhaini Paizi@Fauzi, Malaysia</i></p>
1430 - 1550	<p><i>Chairpersons:</i> <i>Dr Tan Lee Na, Malaysia</i> <i>Dr Low Peh Hueh, Malaysia</i></p>		
1430 - 1450	<p>Antenatal Screening & Care in Fetal NTD Through Delivery <i>Dr Glenn Gardener, Australia</i></p>		
1450 - 1510	<p>Pre Pregnancy Care and Antenatal Journey for Women with Spina Bifida <i>Dr Gayathri Mariappa, Malaysia</i></p>		
1510 - 1530	<p>The State of Fetal Spina Bifida Surgery: Today and Tomorrow <i>Prof Dr Agnieszka Pastuszka, Poland</i></p>	1500 - 1600	<p>Workshop 2: Hospital Visits - The Knowns and Unknowns <i>Moderator:</i> <i>Dr Chan Yean Koon, Malaysia</i></p> <p><i>Facilitators:</i> <i>Ms Siti Zulaikha Mohamad Noor, Malaysia</i> <i>Mr Yee Wing Wei, Malaysia</i></p>
1530 - 1550	<p>The Impact of Fetal Spina Bifida Surgery on Hydrocephalus Management and Care <i>Prof Dr Jeffrey Blount, USA</i></p>		
1600 - 1730	Opening Ceremony	1600 - 1730	Join Us in Sapphire Ballroom
1730	End of Day 1		

Time (hrs)	Sapphire Ballroom	Time (hrs)	Emerald Room	Time (hrs)	Garnet Room	Jasper Room	Amber Room
0700 - 1730	Registration	0700 - 1730	Registration	0700 - 1730	Registration		
0745 - 0830	Free Paper Oral Presentation 1 - Best Free Paper Oral Presentation Award (Judging Session) <i>Assoc Prof Dr Muhammad Kamal Muhammad Abdul Jamil, Malaysia (Chief Judge)</i> <i>Dr Chern Phei Ming, Malaysia</i> <i>Prof Dr Richard Finnell, USA</i> <i>Refer to Page [29]</i>	0730 - 0830	Free Paper Oral Presentation 2 <i>Moderators:</i> <i>Dr Chan Yean Koon, Malaysia</i> <i>Dr Tan Lay Tin, Malaysia</i> <i>Refer to Page [30]</i>	0730 - 0830	Free Paper Oral Presentation 3 <i>Moderators:</i> <i>Dr Azizi Abu Bakar, Malaysia</i> <i>Dr Yusma Asni Yusmido, Malaysia</i> <i>Refer to Page [30]</i>	Free Paper Oral Presentation 4 <i>Moderators:</i> <i>Dr Teh Chee Ming, Malaysia</i> <i>Dr Nurulhuda Zakari@Zakaria, Malaysia</i> <i>Refer to Page [31]</i>	Large Scale Food Fortification Workshop (LSFF): Importance of Measures to Prevent Micronutrient Deficiencies' <i>By Invitation Only</i>
	<i>Chairperson:</i> <i>Dr Chua Li-Shun, Malaysia</i>						
0830 - 0900	Plenary 4: Ethical Issues: A Global Perspective <i>Dr Santosh Karmarkar, India</i>	0830 - 1000	Join Us in Sapphire Ballroom	0830 - 1000	Join Us in Sapphire Ballroom		
0900 - 1000	Plenary 5: Advocacy for Disability Inclusion <i>Dato' Dr Amar-Singh HSS, Malaysia</i>						
1000 - 1030	Tea Break	1000 - 1030	Tea Break	1000 - 1030	Tea Break		
	<i>Chairpersons:</i> <i>Dr Tan Yew Wei, Malaysia</i>						
1030 - 1050	Spinal Cord Release: Sciences Vs Reality <i>Dr Azizi Abu Bakar, Malaysia</i>	1030 - 1110	Roundtable Discussion 2: Transition from Paediatric to Adulthood: When the Voice of the Patient is Becoming More Important than the Voice of the Parents <i>Moderator:</i> <i>Dr Ooi Ai Lee, Malaysia</i> <i>Panellists:</i> <i>Mdm Ayu Primarini, Indonesia</i> <i>Prof Dr Christian Radmayr, Austria</i> <i>Prof Dr Eduardo Tizzano, Spain</i> <i>Mdm Krishnaveni P Krishnan, Malaysia</i> <i>Dr Matthias Axt, Australia</i>	1030 - 1230	Workshop 3: Schooling & Education for Children with Special Needs <i>Moderator:</i> <i>Dr Sharon Anne Khor, Malaysia</i> <i>Speakers:</i> <i>Ms Lim Yee Jin, Malaysia</i> <i>Mr Mustaffa Sultan, Malaysia</i> <i>Mr Ng Swee Guan, Malaysia</i>	Workshop 4: Community Integration: Recreational Activities for Persons With Disabilities <i>Moderator:</i> <i>Dr Tan Lay Tin, Malaysia</i> <i>Speakers:</i> <i>Dr Sivanesan Govindasamy, Malaysia</i> <i>Hj Syed Abd Rahman Syed Hassan, Malaysia</i>	
1050 - 1110	Neurosurgical Perspective in Spina Bifida & Management of Hydrocephalus <i>Prof Dr Dharmendra Ganesan, Malaysia</i>						
1110 - 1130	Early Bladder Management in the Neurogenic Bladder - How to Evaluate and How to Manage <i>Dr Erin McNamara, USA</i>						

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Day 2 : Detailed Programme

25 October 2024 (Friday)

Time (hrs)	Sapphire Ballroom	Time (hrs)	Emerald Room	Time (hrs)	Garnet Room	Jasper Room	Amber Room
1130 - 1150	Is There a Role of Video Urodynamics Study in Spina Bifida <i>Prof Dr Venkat Sripathi, India</i>	1110 - 1240	Youth Forum: Stronger Together - Youth Sharing Experiences about Living with SBH in Terms of Mental Health <i>Ms Kateryna Shcherbyna, Brussels</i> <i>Dr Nebiyat Tesfaye, Ethiopia</i>	1030 - 1230	Workshop 3: Schooling & Education for Children with Special Needs <i>Moderator:</i> <i>Dr Sharon Anne Khor, Malaysia</i> <i>Speakers:</i> <i>Ms Lim Yee Jin, Malaysia</i> <i>Mr Mustaffa Sultan, Malaysia</i> <i>Mr Ng Swee Guan, Malaysia</i>	Workshop 4: Community Integration: Recreational Activities for Persons With Disabilities <i>Moderator:</i> <i>Dr Tan Lay Tin, Malaysia</i> <i>Speakers:</i> <i>Dr Sivanesan Govindasamy, Malaysia</i> <i>Hj Syed Abd Rahman Syed Hassan, Malaysia</i>	
1150 - 1210	Engineered/Fusion Toxins for Treatment of Neurogenic Bladder Dysfunction <i>Dr Hatim Thaker, USA</i>						
1210 - 1240	Innovative Multidisciplinary Approach to Developing Clinical Practice Guidelines for Neurogenic Bladder Management in Children and Adolescents: A Collaborative Endeavor <i>Prof Dr Christian Radmayr, Austria</i>						
1240 - 1430	Lunch, Friday Prayer, Exhibit Visit & Networking	1240 - 1430	Lunch, Friday Prayer, Exhibit Visit & Networking	1230 - 1430	Lunch, Friday Prayer, Exhibit Visit & Networking		
	<i>Chairperson:</i> <i>Dr Amita Vivehanantham, Malaysia</i>						
1430 - 1500	POO Power: Developing a Logical Framework and Network for Managing Neurogenic Bowel <i>Dr Tan Yew Wei, Malaysia</i>	1430 - 1700	Workshop 5: Urology				Large Scale Food Fortification Workshop (LSFF): Importance of Measures to Prevent Micronutrient Deficiencies' <i>By Invitation Only</i>
		1430 - 1450	Successful Management of Incontinence <i>Dr Santosh Karmarkar, India</i>				
1500 - 1530	Bridging the Gap Collaborative Care from Hospital to Home for SBH Patients <i>Assoc Prof Dr Tan Chai Eng, Malaysia</i>	1450 - 1510	Robotic Surgery in Patients with Spina Bifida <i>Dr Hatim Thaker, USA</i>		Workshop 6: Work and Careers for Persons with Spina Bifida & Hydrocephalus <i>Moderator:</i> <i>Ms Cheah Phaik-Lin Jeannie, Malaysia</i> <i>Speakers:</i> <i>Mr Ahmad Zaidin Othman, Malaysia</i> <i>Mdm Faridah Omar, Malaysia</i> <i>Mr Mohamad Firdaus Mohd Jafri, Malaysia</i> <i>Mdm Nor Khairunnisa Mohamad, Malaysia</i> <i>Dr Yusma Asni Yusmido, Malaysia</i>	Workshop 7: Becoming an Advocate in Your City <i>Moderator:</i> <i>Ms K. Aveena Devi, Malaysia</i> <i>Panellists:</i> <i>Mr Daniel Lee, Malaysia</i> <i>Ms Khushbu Ganatra, India</i> <i>Ms Maahi Rudawat, India</i> <i>Ms Miza Marsya Roslan, Malaysia</i>	
1530 - 1700	GAIN Workshop 8 SBH Prevention and Human Rights: The Power of Advocacy and Alliance Building <i>Moderators:</i> <i>Ms Anastasia Smith, USA</i> <i>Ms Kristin Sundell, USA</i> <i>Speakers:</i> <i>Dr Jeffrey Blount, USA</i> <i>Ms Kateryna Shcherbyna, Brussels, Belgium</i> <i>Ms Lara Arosemena, Panama</i> <i>Ms Ruth Nalugya, Uganda</i> <i>Dr Nebiyat Tesfaye, Ethiopia</i> <i>Mr Ludovicus Omollo, Kenya</i> 	1510 - 1700	Workshop/Case Discussion on Urodynamic Study <i>Moderators:</i> <i>Dr Erin McNamara, USA</i> <i>Dr Hatim Thaker, USA</i> <i>Panellists:</i> <i>Prof Dr Christian Radmayr, Austria</i> <i>Dr Lim Li Yi, Malaysia</i> <i>Dr Poongkodi Nagappan, Malaysia</i> <i>Dr Santosh Karmarkar, India</i> <i>Dr Srihari Singaravel, Malaysia</i> <i>Prof Dr Venkat Sripathi, India</i>	1500 - 1700			
1700 - 1730	Poster Judging Session <i>Dr Hatim Thaker, USA</i> <i>Assoc Prof Dr Tan Chai Eng, Malaysia</i>						
1730	End of Day 2						

Day 3 : Detailed Programme

26 October 2024 (Saturday)

Time (hrs)	Sapphire Ballroom	Time (hrs)	Amber Room	Time (hrs)	Emerald Room
0700 – 1600	Registration	0700 – 1600	Registration	0700 – 1600	Registration
0730 – 0830	Free Paper Oral Presentation 5 <i>Moderators:</i> <i>Dr Lim Li Yi, Malaysia</i> <i>Dr Nurulhuda Zakari@Zakaria, Malaysia</i> <i>Refer to Page [31]</i>	0730 – 0830	Free Paper Oral Presentation 6 <i>Moderators:</i> <i>Dr Tan Yew Wei, Malaysia</i> <i>Dr Malini Mahalingam, Malaysia</i> <i>Refer to Page [32]</i>	0730 – 0830	Free Paper Oral Presentation 7 <i>Moderators:</i> <i>Dr Sharon Anne Khor, Malaysia</i> <i>Dr Ooi Ai Lee, Malaysia</i> <i>Refer to Page [32]</i>
	<i>Chairperson:</i> <i>Assoc Prof Dr Muhammad Kamal Muhammad Abdul Jamil, Malaysia</i>				
0830 – 0900	Plenary 6: Trial and Tribulations of Transition Care <i>Dr Erin McNamara, USA</i>		Workshop 9 (Gait Assessment and Orthoses): Understanding the Biomechanics of Different AFOS and How They Affect Gait <i>Mr Fann Lim, Malaysia</i>		Workshop 10 (Occupational Therapy): Getting Independence
0900 – 0930	Plenary 7: Quality of Life and Ageing with Spina Bifida <i>Prof Dr Amaramalar Selvi Naicker, Malaysia</i>			Introduction on What is Tech Tools in Occupational Therapy ? <i>Mr Mohammad Aminuddin, Malaysia</i>	
0930 – 0950	Common Musculoskeletal Problems in Spina Bifida - Rehabilitation Approach <i>Prof Dr Rashidah Ismail @ Ohnmar Htwe, Malaysia</i>	0830 – 1030		Sharing Experience / Clinical: Application Tech Tools and Advance Technology Integrated in Conventional Occupational Therapy Approach <i>Ms Nur Syafiqah Mustaffa Al Bakri, Malaysia</i>	
0950 – 1010	Orthopaedic Management in Spina Bifida <i>Dr Matthias Axt, Australia</i>			Sharing Experience : TROOM for Pediatric Rehabilitation <i>Ms Norsyafiqah Samsuri, Malaysia</i>	
1010 – 1030	Bone Health and Vitamin D Deficiency in Spina Bifida <i>Prof Dr Fong Choong Yi, Malaysia</i>			Q&A	
1030 – 1100	Tea Break	1030 – 1100	Tea Break	1030 – 1100	Tea Break
	<i>Chairperson:</i> <i>Dr Nurulhuda Zakari@Zakaria, Malaysia</i>				
1100 – 1120	Nutritional Challenges in Paediatric Patients with Spina Bifida <i>Dr Cut Hafifah, Indonesia</i>	1100 – 1300	Workshop 11 (Neurogenic Bowel and Bladder): Keeping Continent CIC and Bowel Care		Workshop 12 (Physiotherapy): Physiotherapy in Spina Bifida: Maximising Potential in the Growing Child <i>Ms Christina Anastas, Australia</i>
1120 – 1150	Forum: Advancing Understanding on Urological and Mental Health Needs in an Ageing SBH Community <i>Moderator and Panellist:</i> <i>Mdm Victoria Sandoval Cáceres De Lara, Guatemala</i> <i>Panellists:</i> <i>Dr Margo Whiteford, Scotland</i> <i>Mr Cato Lie, Norway</i>	1100 – 1115	The Physiology and Medical Interventions for Bowel and Bladder Management <i>Dr Tan Yew Wei, Malaysia</i>	1100 – 1300	
		1115 – 1130	Safe Bladder Volume and Frequency of CISC <i>Dr Lim Li Yi, Malaysia</i>		

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Day 3 : Detailed Programme

26 October 2024 (Saturday)

Time (hrs)	Sapphire Ballroom	Time (hrs)	Amber Room	Time (hrs)	Emerald Room
1150 - 1310	Workshop 13: Prenatal Surgery for Fetal Spina Bifida: The Journey from Diagnosis to Surgery & Post Operative Care <i>Panellists:</i> <i>Dr Amita Vivehanantham, Malaysia</i> <i>Prof Dr Agnieszka Pastuszka, Poland</i> <i>Dr Glenn Gardener, Australia</i> <i>Dr Low Peh Hueh, Malaysia</i> <i>Dr Tan Lee Na, Malaysia</i> <i>Dr Teo Shu Ching, Malaysia</i>	1130 - 1215	How to Care for Patient with CIC in Children and Adults: Lecture + Practical Session <i>Ms Farizan Abdul Majid, Malaysia</i>	1100 - 1300	<i>Cont'</i> Workshop 12 (Physiotherapy): Physiotherapy in Spina Bifida: Maximising Potential in the Growing Child <i>Ms Christina Anastas, Australia</i>
		1215 - 1300	Bowel Management Strategies for Children and Adults: Lecture + Practical Session <i>Ms Chua Siew Chien, Malaysia</i>		
1310 - 1400	Lunch, Exhibit Visit & Networking	1310 - 1400	Lunch, Exhibit Visit & Networking	1310 - 1400	Lunch, Exhibit Visit & Networking
1400 - 1600	Workshop 14: Sexual Health in SBH				
1400 - 1420	How to Approach Sexual Topics with Patients <i>Ms Andrea Koh, Malaysia</i>				
1420 - 1440	The Basic Psychosexual Approach for Peoples with Disabilities <i>Prof Dr Hatta Sidi, Malaysia</i>				
1440 - 1500	Management Options in Sexual Dysfunction <i>Dr Lim Li Yi, Malaysia</i>				
1500 - 1600	Q&A				
1600 - 1630	Closing Ceremony <ul style="list-style-type: none"> • Best Free Paper Oral Presentation Award • Best Poster Award • Thank You for Participating 	1600 - 1630	Join Us in Sapphire Ballroom		
	Closing Remarks <i>Ir. Dr Kribanandan Gurusamy Naidu</i> <i>Co-Chair of National Organising Committee for the 30th ICSBH 2024</i>				
1900 Onwards	An Evening of Stars & Strides Fundraising Gala Dinner				

Free Paper Oral Presentation 1 (Best Free Paper Oral Presentation Award)

Sapphire Ballroom | 25 October 2024 | 0730 - 0830 hrs

Presentation Duration: 8 minutes presentation and 2 minutes Q&A

Judges:

Assoc Prof Dr Muhammad Kamal Muhammad Abdul Jamil, Malaysia (Chief Judge)
Dr Chern Phei Ming, Malaysia
Prof Dr Richard Finnell, USA

Oral ID	Topic	Title & Author	Country
BOP01	Country Update	Transition to Fulfilling Aging in People Living with Spina Bifida and Hydrocephalus: Co-developing a Toolkit Laurence Leser, Valérie Poulin, Marie Christine Ouellet, Samuel Turcotte	Canada
BOP02	Country Update	Lack of Knowledge on Spina Bifida and Hydrocephalus Kemigisa Harriet	Uganda
BOP03	Prevention	Fragility Fracture in Spina Bifida Population - A Systematic Review Patrina Chan Ke Jing, Ohnmar Htwe @ Rashidah Ismail, Amaramalar Selvi Naicker	Malaysia

Best Poster Award

Foyer, Poster Board Area | 25 October 2024 | 1700-1730 hrs

Presentation Duration: 3 minutes presentation and 2 minutes Q&A

Judges:

Dr Hatim Thaker, USA
Assoc Prof Dr Tan Chai Eng, Malaysia

Poster ID	Topic	Title & Author	Country
BP01	Multidisciplinary Care	Urological Outcomes of Spinal Dysraphism with Multidisciplinary Management Srihari Singaravel, Ganesh Vythilingam, Anand Sanmugam, Shireen Anne Nah, Tan Yew Wei	Malaysia
BP02	Quality of Life	Quality of Life in 20-year-old Patient with Spina Bifida and Hydrocephalus: A Case Study of Health Issues, Psychosocial Needs and Benefits Of Counseling Widya S. Sari, Wini Widiani	Indonesia
BP03	Quality of Life	Functional Outcome and Quality of Life of Spina Bifida Children in a Tertiary Centre Deepak Singh Peram Singh, Amaramalar Selvi Naicker, Wong Sau Wei, Tan Jen Ern, Ohnmar Htwe @ Rashidah Ismail	Malaysia

Free Paper Oral Presentation 2

Emerald Room | 25 October 2024 | 0730 - 0830 hrs

Oral ID	Topic	Title & Author	Country
OP-2-01	Prevention	Fortified Iodized Salt with Folic Acid (FISFA) as Prevention of Folate - Sensitive Spina Bifida: Feasibility Study Anastasia Arynchnyna Smith , Alexander Arynchnyn, Vijaya Kancharla, Kenneth Anselmi, Inmaculada Aban, Ron Hoogeveen, Lyn Steffen, David Becker, Andrzej Kulczycki, Waldemar A Carlo, Jeffrey P Parker	USA
OP-2-02	Prevention	Status of Global Prevention of Folic Acid Preventable Spina Bifida and Anencephaly in Year 2022 Anastasia Arynchnyna Smith , Wagh, Kaustubh; Kancharla V; Dorsey A; Pachon H; Oakley GP Jr.	USA
OP-2-03	Prevention	Folic Acid Fortified Iodized Salt and Serum Folate Levels in Reproductive - Aged Women of Rural India Madhu Narayana Rao Kottakki , Manda Vv, Kajana Pm, Kancharla V, Bhaganagara-pu Hr, Veerappan V, Ediga A, Mannar V, Diosady L, Oakley Gp Jr.	India
OP-2-04	Interventions	Tea as a Vehicle for Vitamin Fortification: A Phase II Placebo Controlled Cluster - Randomized Trial Hemonta Kr Dutta , Barman Manash P, Gupta Pratim, Kotoky Manas J, Acharyya Bani K, Gogoi JC, Sarmah Podma P, Sabhapondit Santanu, Chowdhury Pritam, Vora Ravindra M, Antony AC.	India
OP-2-05	Prevention	Optimizing Folate Supplementation Strategies: A Review of 5-Methylhydrofolate Supplementation and Folate Levels in Women of Childbearing Age Radha Krishna , Naicker As, Shahzad H, Abdalla Mmi	Malaysia

Free Paper Oral Presentation 3

Garnet Room | 25 October 2024 | 0730 - 0830 hrs

Oral ID	Topic	Title & Author	Country
OP-3-01	Country Update	Bi-National Survey of Early Management of Tethered Cord Syndrome in Children Carylyn Lim , Antoinette Botman	Australia
OP-3-02	Multidisciplinary Care	An Updated Approach to The Multidisciplinary Clinic Carylyn Lim , Browne, C., Daley, D., Davis, J. Lask, A., Mitchell, R.	Australia
OP-3-03	Early Detection & Screening	Use of High-Resolution Anorectal Manometry for Pelvic Floor Function Assessment in Patients with Closed Spinal Dysraphism Alina Korsak , Volodymyr Likhodiievskyi, Volodymyr Gonchar, Serhii Olefir, Andrii Akymov	Ukraine
OP-3-04	Genetics	Prenatal Exome Experience in Fetuses with Malformations: Results in Recurrent Cases of Neural Tube Defects Finnell, R., Eduardo Tizzano , Curfs, L.M.G., Scheres, J., Roozen, S.	Spain
OP-3-05	Genetics	Genetics and Neural Tube Defects Eduardo Tizzano , Fernandez -Alvarez P, Abulí A, Leno J, Valenzuela I, Codina-Solà M, Lasa A, Sánchez-Duran MA, Rodó C, Cueto AM, Camacho J, Martínez E, Vazquez J, García-Arumí E	Spain

Free Paper Oral Presentation 4

Jasper Room | 25 October 2024 | 0730 - 0830 hrs

Oral ID	Topic	Title & Author	Country
OP-4-01	Interventions	Ultrasound Characteristics Of Fetal Brain Structures In Chiari II - Results Of Spina Bifida Intrauterine Correction Liliyana Ciugunova , Kostyukov K., Syrkashev E., Narogan M., Bykova Yu., Nikolaeva A., Shmakov R., Gladkova K., Sakalo V., Berdichevskya E., Zinenko D., Ionov V., Trofimov D.	Russian Federation
OP-4-02	Quality of Life	Vitamin D Deficiency In Children And Adolescents With Spina Bifida And Its Association With Musculoskeletal Complications Fathmath Iyaany Abdul Matheen , Ohnmar Htwe; Wong Sau Wei; Tan Jen Ern Amaramalar Selvi Naicker	Malaysia
OP-4-03	Epidemiology	Challenges In The Management Of Neurogenic Bladder And Bowel Dysfunction In Spinal Dysraphism : Result Of A National Survey Srihari Singaravel, Ganesh Vythilingam, Anand Sanmugam, Shireen Anne Nah, Mazlina Mazlan, Rashidah Ismail @ Ohnmar Htwe, Amaramalar Selvi Naicker, Tan Yew Wei	Malaysia
OP-4-04	Multidisciplinary Care	A Decade Of Multidisciplinary Care For Spinal Dysraphism: Incidence And Efficiency Evaluation Shaza Alyssa Shahroni , Don Evana Ezrien Binti Shaadon Zubir, Dharmendra Ganesan, Srihari Singaravel, Sakinah Sabirin, Limin Li, Choong Yi Fong, Yew Wei Tan	Malaysia

Free Paper Oral Presentation 5

Sapphire Ballroom | 26 October 2024 | 0730 - 0830 hrs

Oral ID	Topic	Title & Author	Country
OP-5-01	Advocacy and Empowerment	Reproductive Education and Sexual Abuse Among Adults with Spina Bifida: A Mixed Methods Study Betsy Hopson , Jeffrey Blount, Donald Lein, Brandon Rocque, Carmen Tong	USA
OP-5-02	Multidisciplinary Care	Alabama's First Primary Care Medical Home for Patients with Medical Complexity: What Our Patients with Spina Bifida are Teaching Us Betsy Hopson , Carlie Stein Somerville, Madeline Eckenrode, Jeffrey Blount, Brandon Rocque	USA
OP-5-04	Education	Global Health and Disability: The Experience of Disability Day and The Spina Bifida Global Learning Collaborative Melinda Rocchi , Semhal Getachew Teka, Mary M., Elly Kutwa	Sweden
OP-5-05	Advocacy and Empowerment	Beyond Barriers: Unveiling the Sexual Function Challenges in Individuals with Spina Bifida Maahi Rudawat	India

Free Paper Oral Presentation 6

Amber Room | 26 October 2024 | 0730 - 0830 hrs

Oral ID	Topic	Title & Author	Country
OP-6-01	Epidemiology	Associations Between Periconceptional Exposure to Extreme Ambient Heat and Neural Tube Defects in Georgia, USA Anastasia Arynchyna Smith , LaPointe, S, Lauren Beagle, Xiaping Zhang, Abby Mutik, Howard Chang, Audrey Gaskins	USA
OP-6-02	Multidisciplinary Care	Morphological State of the Anorectal Region in the Experimental Model of Spina Bifida Volodymyr Gonchar	Ukraine
OP-6-03	Early detection & screening	Ages and Stages Questionnaires: Feasibility of Online Survey for Post-shunt Hydrocephalus Follow-up Hemonta Kr Dutta	India
OP-6-04	Early detection & screening	Prone Position Magnetic Resonance Imaging and Surgical Outcomes in Occult Tethered Cord Syndrome: Case Series Hsin Hung Chen	Taiwan, ROC
OP-6-05	Multidisciplinary Care	New Method Of Surgical Treatment Of Perineal Disorders In Children With Spina Bifida Volodymyr Gonchar	Ukraine

Free Paper Oral Presentation 7

Emerald Room | 26 October 2024 | 0730 - 0830 hrs

Oral ID	Topic	Title & Author	Country
OP-7-01	Quality of Life	The Importance of Accessibility Cato Lie	Norway
OP-7-02	Epidemiology	Functioning and Disability Profiles of Individuals with Spina Bifida and Hydrocephalus in Jakarta, Indonesia Rizky Kusuma Wardhani , Laksmításari B; Wahyuni LK	Indonesia
OP-7-03	Quality of Life	Factors Associated with Quality of Life in Indonesian Children and Adults with Spina Bifida Budiati Laksmításari , Budi Laksmításari, Rizky Kusuma Wardhani, Angela J	Indonesia
OP-7-04	Quality of Life	Supporting the Independence of Young Adults with Spina Bifida and or Hydrocephalus Kateryna Shcherbyna , Laura Rosillo Beneyto, Ajok Proscovia, Rereloluwa Adeolu, Mirela Bukovac, Malik Armughan Ali, Rebecca Austin, Samuel Opeyemi, Patricia Albertová, Nebiyat Testafaye, Jurn Anthonis, Chen Miaohua, Harichandana Mynampati	Belgium
OP-7-05	Miscellaneous	A Qualitative Study of Vulnerability in Individuals with Spina Bifida: Medical Students' Perspective Budiati Laksmításari , Luh Karunia Wahyuni, Rizky Kusuma Wardhani, Josephine Angela	Indonesia

Poster Presentation

Poster ID	Topic	Title & Author	Country
PP01	Country Update	Long Term Urological Outcomes And Bladder Management Protocols In Spina Bifida Patients In Australia Elizabeth Dally	Australia
PP02	Epidemiology	Micronutrient Biomarkers For Neural Tube Defects Risk In Rural India Manda Venkata Vijaya Sekhar , Kancherla V, Kottakki Mnr, Pattisapu Jv, Oakley Gp Jr.	India
PP03	Interventions	Follow Up Of Diagnostic Findings In Two Cases Of Neurogenic Lower Urinary Tract Dysfunction In Pediatric Spina Bifida Wini Widiani , Edvina	Indonesia
PP04	Miscellaneous	Uncommon Monoparesis Of Lower Extrimity In Infantile Spina Bifida: A Case Report Dewi Masrifah Ayub , Nurul Kusuma W, Noor Idha H, S.M. Mei Wulan, Ratna D. Soebadi	Indonesia
PP05	Multidisciplinary Care	Multidisciplinary Team Management Of A Patient With Neuromuscular Scoliosis and hip Dislocation Sharon Anne Khor, Ng Chiew Ling, Karim Ayman Ghazi Khaled , Karim Khaled, Lee Chon Kit	Malaysia
PP06	Prevention	A Systematic Review on Risk Factors that Leading to Deterioration in Ambulation in Adult Spina Bifida Zulasri azan bin Md Zain , Ohnmar Htwe @ Rashidah Ismail, Amaramalar Selvi Naicker	Malaysia
PP07	Quality of Life	Advancing Spina Bifida Research - Insights From Malaysia Kiranpreet Kaur , Nurul Firdausi Hasnol Basri, Chung Tze Yang	Malaysia
PP08	Quality of Life	Wheelchaircheck.com: A Screening Tool To Empower Wheelchair Users to Reduce Wheelchair-Related Health Problems In Spina Bifida Olga De Wit , Valent, L, Faber, W	The Netherlands
PP09	Prevention	Spina Bifida Spina Bifida as A Cause of Pelvic Prolapse in Women Konstantin Honchar	Ukraine

INTELLECTUAL DISCUSSION ON SPINA BIFIDA: COMMUNITY & HEALTHCARE AWARENESS ARE WE THERE YET?

📅 Thursday | 24 October 2024 ⌚ 1400 - 1500 hrs 📍 Amber Room

Introduction:

This session brings together clinicians and the SBH community in an open debate and discussion format to discuss the achievements, progress and challenges faced by the community and healthcare awareness on Spina Bifida care

Goals:

Attendees will gain valuable insights into the progress and challenges in Spina Bifida care, empowering them to advocate for improved healthcare awareness and community support



HOSPITAL VISITS: THE KNOWN & UNKNOWN

📅 Thursday | 24 October 2024 ⌚ 1500 - 1600 hrs 📍 Amber Room

Introduction:

This session is an interactive open sharing from the perspective of the SBH community and their families about their experiences with healthcare services. Attendees will hear from national and international participants

Goals:

- ☀ To discover more about the healthcare experience of the SBH community and their families across the globe
- ☀ To identify areas of improvement in the healthcare experience of the SBH community and their families



DR CHAN YEAN KOON
Rehabilitation Physician
MODERATOR



**MS SITI ZULAIKHA
MOHAMAD NOOR**
Occupational Therapist
SPEAKER



MR YEE WING WEI
Physiotherapist
SPEAKER

SCHOOLING & EDUCATION FOR CHILDREN WITH SPECIAL NEEDS

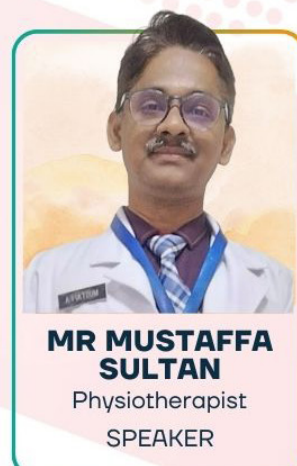
📅 Friday | 25 October 2024 ⌚ 1030 - 1230 hrs 📍 Garnet Room

Introduction:

This session aims to provide information and knowledge on schooling and education; from hospital to community. This session is an open sharing from the perspective of SB and their family as well as the perspective of clinicians on this topic. Attendees will hear from national and international participants.

Goals:

Children with SB face challenges to get enrolled in school. Parents, educators and health care providers play important roles to facilitate this process. Healthcare providers should strive to optimise the medical condition for the SB child to maximise physical function. Family members should provide continuous support. Educators must enable equitable access to education enable children with SB to reach their fullest psychosocial potential.



COMMUNITY INTEGRATION: RECREATIONAL ACTIVITIES FOR PERSONS WITH DISABILITIES

📅 Friday | 25 October 2024 ⌚ 1030 - 1230 hrs 📍 Jasper Room

Introduction:

A full life is made up of not just basic living skills. Recreations and socialisation add meaning and richness to the life of people with special needs, especially people with spinal bifida, to improve quality of life, with safe, comfortable and fun activities in the community

Goals:

- ☀️ Participation in recreational activities with others can lead to increases in self-confidence, happiness, morale, and life satisfaction, as well as an increase in muscle strength, sense of well-being, flexibility, balance, and coordination
- ☀️ Resources are available in Malaysia to promote socialisation and recreation for persons with special needs. The key of this session is to discover resources to find fun and interesting recreational activities for persons with special needs, especially people with spinal bifida



DR TAN LAY TIN
Paediatrician
MODERATOR



**HJ SYED ABD
RAHMAN SYED
HASSAN**
Ambassador of
DiveHeart Malaysia
SPEAKER



**DR SIVANESAN
GOVINDASAMY**
Deputy President of
Special Olympics Malaysia
SPEAKER

UROLOGY WORKSHOP

📅 Friday | 25 October 2024 ⌚ 1430 - 1700 hrs 📍 Emerald Room

Introduction:

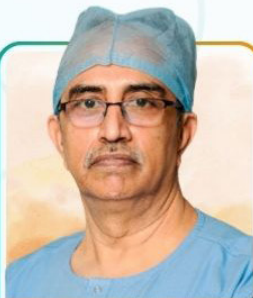
The Urodynamics Course provides a comprehensive understanding of urodynamics and its application in spina bifida patients. This 2-hour course examines various urodynamic cases specific to spina bifida, highlighting the relevance of urodynamics in managing urinary issues. Participants will gain knowledge in interpreting urodynamic findings, implementing appropriate interventions, and optimising bladder function.

Goals:

- ✳ Enhance participants' understanding of urodynamics principles and applications through real-life case discussions
- ✳ Improve participants' diagnostic skills by recognising abnormal urodynamic patterns and relating them to clinical presentations in spina bifida patients
- ✳ Optimise patient care by equipping participants with evidence-based strategies to address urinary complications, improve bladder function, and enhance overall quality of life for individuals with spina bifida



DR ERIN MCNAMARA
Paediatric Urologist
USA



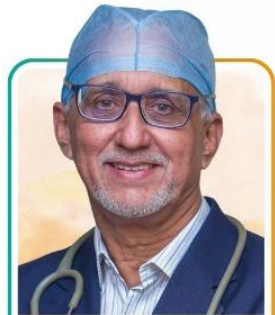
PROF DR VENKAT SRIPATHI
Paediatric Urologist
INDIA



DR HATIM THAKER
Paediatric Urologist &
Surgeon Scientist
USA



PROF DR CHRISTIAN RADMAYR
Paediatric Urologist
AUSTRIA



DR SANTOSH KARMARKAR
Paediatric Surgeon
INDIA



DR POONGKODI NAGAPPAN
Urologist
MALAYSIA



DR SRIHARI SINGARAVEL
Paediatric Urologist
MALAYSIA



DR LIM LI YI
Urologist
MALAYSIA

WORK AND CAREERS FOR PERSONS WITH SPINA BIFIDA & HYDROCEPHALUS

📅 Friday | 25 October 2024 ⌚ 1500 - 1700 hrs 📍 Garnet Room

Introduction:

This session focuses on information/knowledge on work and career opportunities. This session is an open sharing from the perspective of a working SB adult, SOCSO and the role of clinician in work preparation and readiness

Goals:

Facilitating and discovering return-to-work opportunities by empowering individuals with spina bifida and hydrocephalus



**MR AHMAD ZAIDIN
OTHMAN**
Senior Case Manager
of PERKESO
SPEAKER



**MDM FARIDAH
OMAR**
Physiotherapist
SPEAKER



**MR MOHAMMAD
FIRDAUS MOHD
JAFRI**
SBH Individual
SPEAKER



**MDM NOR
KHAIRUNNISA
MOHAMAD**
Occupational Therapist
SPEAKER



**DR YUSMA ASNI
YUSMIDO**
Rehabilitation Physician
SPEAKER

BECOMING AN ADVOCATE IN YOUR CITY

📅 Friday | 25 October 2024 ⌚ 1500 - 1700 hrs 📍 Jasper Room

Introduction:

This curated panel session talks about the basic fundamentals you need to have, to become a voice for your community. It will be a impactful sharing session amongst 4 established advocates that will share their tools and tricks on how you can make difference in the world

Goals:

- 🌟 Gain tools on becoming an impactful advocate
- 🌟 A starter kit of points on how to map out your path into advocacy
- 🌟 Learn about the attributes to build a healthy mindset for yourself



MS K. AVEENA DEVI
Mixed Media Artist,
Author & Motivational
Speaker
MODERATOR



MR DANIEL LEE
Motivational Speaker
SPEAKER



MS KHUSHBU GANATRA
Co-Founder and
Director of Walk n
Wheels Foundation
SPEAKER



MS MAAHI RUDAWAT
Advocate & Member of
the Spina Bifida
Foundation India
SPEAKER



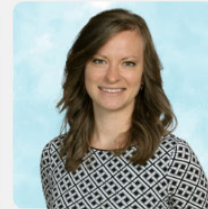
MS MIZA MARSYA ROSLAN
UNICEF Young Leader
& PWD Advocate
SPEAKER

SBH PREVENTION AND HUMAN RIGHTS: THE POWER OF ADVOCACY AND ALLIANCE BUILDING

FRIDAY | 25 OCTOBER 2024 | 1530 - 1700 HRS | SAPPHIRE BALLROOM

This session will present the basic elements of a national-level advocacy campaign to establish or strengthen food fortification programs to reduce the prevalence of spina bifida and hydrocephalus. Topics that will be discussed include building national alliances for food fortification across sectoral and interest groups, establishing productive advocacy dialogues with key decision makers from the public and private sector, and utilizing upcoming global opportunities such as the Nutrition for Growth Summit and the World Health Assembly to mobilize greater commitment and accountability for food fortification progress at the national level. The session will also address advocacy for equality, inclusion, and human rights for those affected by SBH and how advocacy efforts for prevention and human rights can be combined. Leaders representing spina bifida associations in Ethiopia, Panama, and Uganda will share their personal advocacy experiences.

Moderators:



ANASTASIA SMITH

COORDINATOR, GLOBAL ALLIANCE FOR THE PREVENTION OF SPINA BIFIDA AND CLINICAL RESEARCH MANAGER, DEPT. OF NEUROSURGERY, CHILDREN'S OF ALABAMA



KRISTIN SUNDELL

SENIOR ADVOCACY SPECIALIST, GAIN

Speakers:



JEFFREY BLOUNT

MD, PAEDIATRIC NEUROSURGEON AND GLOBAL ALLIANCE FOR THE PREVENTION OF SPINA BIFIDA



KATERYNA SHCHERBYNA

PROJECT OFFICER, INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS



LARA AROSMENA

FOUNDER AND PRESIDENT, ZERO LIMITE ESPINA BIFIDA PANAMA



RUTH NALUGYA

EXECUTIVE DIRECTOR, SPINA BIFIDA AND HYDROCEPHALUS ASSOCIATION, UGANDA



NEBIYAT TESFAYE

MD, TECHNICAL DIRECTOR, REACH ANOTHER FOUNDATION, ETHIOPIA



LUDIVICUS OMOLLO

SENIOR ASSOCIATE GLOBAL ADVOCACY, GLOBAL ALLIANCE FOR IMPROVED NUTRITION

Agenda:

Introductions and Welcome

What is food fortification? What is the role of food fortification in preventing NTDs? Introducing the World Health Assembly resolution on food fortification as an example of effective alliance building and advocacy.

Jeffrey Blount

The need for a human rights-based approach towards prevention

Kateryna Shcherbyna

Panel presentation – Advocacy stories and experiences from Ethiopia, Panama, and Uganda

Lara Arosmena, Ruth Nalugya, Nebiyat Tesfaye

Who are the duty bearers responsible for national food fortification programs? Alliance-building for more effective advocacy. Introducing the Nutrition for Growth Summit as an upcoming advocacy opportunity.

Introducing the LSFF advocacy toolkit

Ludivicus Omollo

Group Discussion

Plenary Discussion

GAIT ASSESSMENT & ORTHOSES WORKSHOP: UNDERSTANDING THE BIOMECHANICS OF DIFFERENT AFOS AND HOW THEY AFFECT GAIT

📅 Saturday | 26 October 2024 ⌚ 0830 - 1030 hrs 📍 Amber Room

Introduction:

This program is designed to provide healthcare professionals with a comprehensive understanding of ankle-foot orthoses (AFOs) and their impact on gait patterns. By exploring the biomechanics of different AFO designs, participants will gain valuable insights into how these devices can be effectively prescribed to address various gait abnormalities



MR FANN LIM
CPO

USA Certified
Prosthetist Orthotist
MALAYSIA

Goals:

- ✳ Enhance knowledge and skills by equipping participants with a deep understanding of AFO biomechanics, improve gait assessment skills, and master fitting and check-out procedures
- ✳ Promote evidence-based practice by fostering the use of evidence-based principles in the selection, prescription, and fitting of AFOs, ensuring optimal patient outcomes



OCCUPATIONAL THERAPY WORKSHOP: GETTING INDEPENDENCE

📅 Saturday | 26 October 2024 ⌚ 0830 - 1030 hrs 📍 Emerald Room

Introduction:

Occupational therapy is a dynamic healthcare profession dedicated to helping individuals and families achieve independence, functionality, engagement, and participation in daily life activities, all with the goal of enhancing quality of life. While rehabilitation remains a core aspect, occupational therapy has evolved to include a broader perspective that goes beyond recovery. Using a holistic approach, occupational therapists tailor their strategies to the unique needs and goals of each individual, ensuring that interventions are personalized and meaningful

Goals:

- ✳ How advanced technology is becoming a part of occupational therapy approaches
- ✳ There are many opportunities for rehabilitation, making the process more enjoyable for children
- ✳ Regaining potential, adapting to the evolving field of rehabilitation, and achieving optimal goals are essential

Introduction on What is Tech Tools in Occupational Therapy

MR MOHAMMAD AMINUDDIN
Occupational Therapist
MALAYSIA



Sharing Experience / Clinical: Application Tech Tools and Advance Technology Integrated in Conventional Occupational Therapy Approach

MS NUR SYAFIQA H MUSTAFFA AL BAKRI
Occupational Therapist
MALAYSIA



Sharing Experience: TROOM for Paediatric Rehabilitation

MS NORSYAFIQA H SAMSURI
Rehab Assistant Manager
MALAYSIA



Facilitators:

MS GOH SHI YING,
Occupational Therapist, Malaysia

MS NUR KHALILATUL AMLA KAMAL SUBKI,
Occupational Therapist, Malaysia

NEUROGENIC BOWEL & BLADDER WORKSHOP: KEEPING CONTINENT CIC AND BOWEL CARE

 **Saturday | 26 October 2024**  **1100 - 1300 hrs**  **Amber Room**

Introduction:

This workshop is designed to equip healthcare professionals and caregivers with essential skills for managing neurogenic bladder and bowel conditions, particularly in individuals with spinal dysraphism. Neurogenic dysfunction can lead to significant health complications if not properly managed. The workshop emphasises a comprehensive understanding of physiology, intervention techniques, and patient care, ensuring that participants gain practical knowledge that can be applied in both home and clinical settings.

Goals:

- ✳ Understand the physiology of bowel and bladder function in both health and disease, focusing on neurogenic conditions
- ✳ Learn and apply appropriate medical interventions, including clean intermittent catheterisation (CIC) and bowel management strategies
- ✳ Master practical skills in aseptic techniques and catheter care for safe, effective patient management



DR TAN YEW WEI

The Physiology & Medical Interventions for Bowel and Bladder Management

Paediatric Surgeon
MALAYSIA



DR LIM LI YI

Safe Bladder Volume & Frequency of CISC

Urologist
MALAYSIA

LECTURE AND PRACTICAL SESSIONS:



**MS FARIZAN
ABDUL MAJID**

Nurse
MALAYSIA



**MS CHUA SIEW
CHIEN**

Clinical Nurse
Educator
MALAYSIA

Session 1

Bowel Management Strategies for Children & Adults

Session 2

How to Care for Patient with CIC in Children & Adults

Facilitators:

MS RAJA NURUL FAIZAH RAJA HAMZAH

MS HAZATI RAYA

Paediatric Specialist Continence Nurses
Malaysia

PHYSIOTHERAPY IN SPINA BIFIDA: MAXIMISING POTENTIAL IN THE GROWING CHILD

📅 Saturday | 26 October 2024 ⌚ 1100 - 1300 hrs 📍 Emerald Room

Introduction:

This session will explore the Australian perspective on physiotherapy management for children with Spina Bifida and Spinal Dysraphism. It aims to address the complex and dynamic factors that influence physical activity and participation in these children. Attendees will gain insights into the evidence-based approaches for assessment and treatment, as well as understand the theoretical rationale behind treatment choices when evidence is limited

Goals:

- ✿ The Perth Children's Hospital Perspectives
- ✿ Assessment & Treatments Choices
- ✿ The Importance of Surveillance
- ✿ Optimising Mobility
- ✿ Promoting Participation
- ✿ Case Studies



**MS CHRISTINA
ANASTAS**

Senior Physiotherapy (Spinal
Rehabilitation)
AUSTRALIA

PRENATAL SURGERY FOR FETAL SPINA BIFIDA: THE JOURNEY FROM DIAGNOSIS TO SURGERY & POST OPERATIVE CARE

📅 Saturday | 26 October 2024 ⌚ 1150 - 1310 hrs 📍 Amber Room

Introduction:

A sharing and discussion of referral pathway for the novel prenatal surgical option in Malaysia for parents with fetal spina bifida

Goals:

- ✿ Diagnosis
- ✿ Treatment Options
- ✿ Referral Pathway
- ✿ Overview on Surgical Techniques
- ✿ Anaesthetic Considerations
- ✿ Post-Operative Care

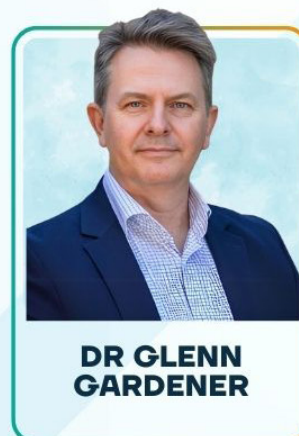


Sarawak General Hospital, MALAYSIA



**Medical University of Silesia,
POLAND**

Fetal Surgeon,
Paediatric Surgeon &
Paediatric Urologist



**Mater Mothers' Hospital,
AUSTRALIA**

Maternal Fetal
Medicine Specialist

SEXUAL HEALTH IN SPINA BIFIDA & HYDROCEPHALUS

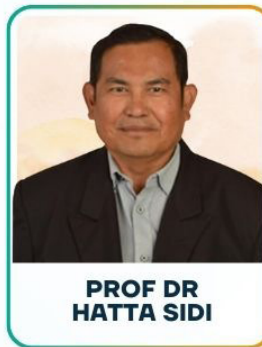
📅 Saturday | 26 October 2024 ⌚ 1400 - 1600 hrs 📍 Sapphire Ballroom

Introduction:

This session delves into the complexities of sexual health, focusing on effective communication, cultural sensitivity, and tailored approaches for patients with disabilities and sexual dysfunction

Goals:

Empower healthcare professionals to address patients' sexual health needs comprehensively, improving their overall well-being through open dialogue, understanding diverse perspectives, and implementing appropriate management strategies



**PROF DR
HATTA SIDI**

The Basic Psychosexual Approach for Persons with Disabilities

Psychiatrist
MALAYSIA



MS ANDREA KOH

How to Approach Sexual Topics with Patients

Sexologist & Counsellor
MALAYSIA



DR LIM LI YI

Management Options in Sexual Dysfunction

Urologist
MALAYSIA

Keynote Abstract

Sapphire Ballroom | 24 October 2024 | 1045 - 1115 hrs

The Biology Of Neural Tube Defects: From Prevention Efforts To Stem Cell Therapeutics

Prof Dr Richard Finnell

*Distinguished Professor of Paediatric Genetics,
Baylor College of Medicine, USA*

Neural tube defects (NTDs) are the second most prevalent class of major human congenital malformations. NTDs refer to structural malformations of the brain and spinal cord that affect neural tube closure (NTC). A primary modifier of NTD risk is the maternal folate (vitamin B9) status. The prevalence of NTDs has been drastically reduced by oral intake of folic acid (FA) but continues to range between 0.5-2 in 1000 live births, even after folic acid fortification. There are approximately 2,300 NTD-affected pregnancies in the US each year, whose lifetime medical costs are estimated to be \$560,000 per child or \$1.68 billion per year nationwide. Multiple environmental, genetic, nutritional, or a combination of these diverse factors underlie the etiology of these defects. The complexity of NTD etiology and the various mechanisms through which these genetic and environmental factors interact make prevention and treatment a tall order. Effective prenatal diagnosis and intervention strategies in treating NTDs, especially spina bifida in utero, will transform the lives of patients and prevent their recurrence in future pregnancies of mothers with previous history. Novel therapies are desperately needed to eliminate recurrence of NTDs in affected families and in FA-non-responsive cases that currently cannot be prevented. In this presentation, I will attempt to better understand just how these genetic and environmental factors ultimately translate into the biological forces that drive or perturb NTC, which is of paramount importance for developing next-generation treatment and intervention paradigms, especially early in utero surgical repair. By developing and utilizing novel technologies and therapies to study and modulate NTC biomechanics, our research program makes a significant contribution to understanding the mechanisms of NTD pathology and developing next generation therapies.

Country Update

Sapphire Ballroom | 24 October 2024 | 0830 - 0835 hrs

Country Update: Accessibility to Prevention and Care in Latin America

Mdm Elena Zappoli

¹Asociación para Espina Bifida e Hidrocefalia (APEBI), Buenos Aires, Argentina

Background: Prevention and rehabilitation as key priorities for persons affected by Spina Bifida and Hydrocephalus in Latin American countries. The current situation in Latin America is characterised by lack of access to basic services and food insecurity, as well as the fragility of health, social protection systems and especially the lack of rehabilitation.

Methods: A regional network for Latin American countries was established named RELAEBHI. This network is dedicated to expanding and defining objectives and advocacy initiatives for the construction of a strategic vision and regional strengthening. As such, RELAEBHI brings together leaders and organisations dedicated to SBH in the region, for research, dissemination, exchange, education and strengthening of programs and actions aimed at improving the quality of life of people with SBH and their families.

Results: In this presentation an overview will be presented on community-based approaches by Latin-American Members from Bolivia, Ecuador, Nicaragua, Dominican Republic, Mexico, Guatemala, Colombia, Paraguay, Costa Rica, Panama, and Chile will be provided.

Discussion: The Latin American Network provides its members with important resources and opportunities to build capacity. To strengthening the collaboration with the partners both locally and regionally, future plans for organising the next meeting of the Latin American network in 2024-2025 will be shared.

Country Update

Sapphire Ballroom | 24 October 2024 | 0835 - 0840 hrs

Country Update: Empowering Lives Through Spina Bifida And Hydrocephalus Initiatives In Uganda

Ms Ruth Nalugya

SHAU Spina Bifida and Hydrocephalus Association Uganda

Kampala, Uganda

Background: In the dynamic landscape of disability rights and inclusion, organizations of persons with disabilities (OPDs) are at the forefront of driving change. Among these trailblazers stands the Spina Bifida and Hydrocephalus Association Uganda (SHAU). Established in 2018, SHAU has emerged as a beacon of hope for individuals living with spina bifida and hydrocephalus, as well as their dedicated caregivers. SHAU operates from its headquarters in Kampala, Uganda's capital city, with strategically positioned regional offices across the country. SHAU's vision is to create an inclusive society—one that not only supports affected families but also empowers individuals with spina bifida and hydrocephalus for long-term, independent living.

Method: SHAU employs a multifaceted approach, rooted in targeted interventions. These include inclusive health, rehabilitation, organizational capacity strengthening, human rights advocacy, and inclusive education. Our core values—diversity, equity, compassion, and integrity—guide our work, ensuring transparency and continuous improvement through robust monitoring and evaluation.

Findings: SHAU's country-level progress reflects positive shifts in disability management and inclusion. Improved organizational governance and management, enhanced access to social services, and increased participation of persons with spina bifida and hydrocephalus in local and national decision-making processes underscore SHAU's commitment to inclusivity. Community engagements and collaborations remain focal points, ensuring the sustainability of our efforts.

Discussion: Disability organizations empower individuals with lived experiences, fostering authentic and sustainable solutions. Collaboration, resource security, and continuity drive long-term impact, making disability inclusion a fundamental right.

Country Update

Sapphire Ballroom | 24 October 2024 | 0840 - 0845 hrs

Country Update: Understanding and Welcoming People with Spina Bifida and Hydrocephalus

Leser Laurence¹; Rougagnou Margaux²; Barbeau Mathilde³; Coupal Danielle⁴; Perrault- Rousseau Laurence⁵; Fortin Nicholas⁶; Guillet François⁷; Productions Arborescence⁸; ⁹And all the members who participated in our brainstorming sessions.

¹Leser Laurence, info@spina.qc.ca, Director Spina-bifida hydrocéphalie Québec, Canada

²Rougagnou Margaux, Coordinator Spina-bifida hydrocéphalie Québec

³Barbeau Mathilde, Doctor and person living with SBH

⁴Coupal Danielle, Parent of an adult living with SBH and caregiver

⁵Perrault-Rousseau Laurence, Person living with SBH, employee and employer

⁶Fortin Nicholas, Gym teacher

⁷Guillet François, Spouse and care giver of a person living with SBH

⁸Productions Arborescence

⁹And all the members who participated in our brainstorming sessions.

Abstract: The members of Spina-bifida hydrocéphalie Québec often share with us their dismay at people's lack of understanding of their disabilities. Together, we looked for the best way to help them better be understood and integrate into their communities.

Background: SBH is a poorly understood disability. It is not visible to everyone and difficult to explain. It's hard to explain at school, in the workplace, it's hard to express your needs to your caregivers and vice versa. Following two consultations with members of the association, we developed four video clips around four themes: creativity, respect, openness, and looking beyond disability.

Procedure: Interviews were conducted with people living with the conditions, parents, caregivers, professionals, spouses, and relatives of people living with SBH. We have collected their words, their successes, their challenges, their concerns. From there, we developed scripts and prepared shooting days. The capsules are a mix of people filmed and animations that illustrate their words.

Expected Results: These capsules are a tool that will allow people with SBH to be better understood in their communities. They will serve as a support to present their disability and find concrete solutions in their communities to the challenges they may have. These videos were made in French but are subtitled in French and English, which will allow for wider distribution.

Discussion: We are convinced that these capsules represent an essential element of awareness for people with SBH.

Country Update

Sapphire Ballroom | 24 October 2024 | 0845 - 0850 hrs

Country Update: Norwegian Association for Spina Bifida and Hydrocephalus

Ms Liv Tørring

Ryggmargsbrokk- og Hydrocephalusforeningen (RH-foreningen)
Norway

Background: In the dynamic landscape of disability rights and inclusion, organizations of persons with disabilities (OPDs) are at the forefront of driving change. Among these trailblazers stands the Spina Bifida and Hydrocephalus Association Uganda (SHAU). Established in 2018, SHAU has emerged as a beacon of hope for individuals living with spina bifida and hydrocephalus, as well as their dedicated caregivers. SHAU operates from its headquarters in Kampala, Uganda's capital city, with strategically positioned regional offices across the country. SHAU's vision is to create an inclusive society—one that not only supports affected families but also empowers individuals with spina bifida and hydrocephalus for long-term, independent living.

Method: ASHAU employs a multifaceted approach, rooted in targeted interventions. These include inclusive health, rehabilitation, organizational capacity strengthening, human rights advocacy, and inclusive education. Our core values—diversity, equity, compassion, and integrity—guide our work, ensuring transparency and continuous improvement through robust monitoring and evaluation.

Findings: SHAU's country-level progress reflects positive shifts in disability management and inclusion. Improved organizational governance and management, enhanced access to social services, and increased participation of persons with spina bifida and hydrocephalus in local and national decision-making processes underscore SHAU's commitment to inclusivity. Community engagements and collaborations remain focal points, ensuring the sustainability of our efforts.

Discussion: Disability organizations empower individuals with lived experiences, fostering authentic and sustainable solutions. Collaboration, resource security, and continuity drive long-term impact, making disability inclusion a fundamental right.

Country Update

Sapphire Ballroom | 24 October 2024 | 0850 - 0855 hrs

Country Update: Scotland

Dr Margo Whiteford

Chair of SBH Scotland; margo.whiteford@sbhscotland.org.uk

Spina Bifida Hydrocephalus Scotland, The Dan Young Building, 6 Craighalbert Way, Dullatur, Glasgow, G68 OLS, Scotland

Background: An overview of how SBH Scotland is meeting the support needs of people with spina bifida and hydrocephalus in Scotland.

Methods: Discussions were had with SBH Scotland staff and responses analysed from a survey issued in August 2023 to our members. The survey received 19 responses.

Findings: Our direct services team consists of Support Workers, Nurse Specialists and a Mental Health Counsellor. They provide joined up support through early intervention to avoid members reaching crisis. We have also appointed a Youth Worker whose focus is on supporting young people in transitioning into adulthood which can be challenging in Scotland. Recently, the cost-of-living crisis has been an acute challenge for our members. 58% of members told us the cost-of-living crisis has affected their daily life, with 60% saying they are worried 'a lot' or a 'great deal' about this. Areas of concern were around paying bills, heating homes, accessing hobbies/interests, and looking after health and wellbeing. Therefore, we have been providing more direct support to tackle these issues through our income maximisation service. Our new Adulthood and Ageing project is available to all service users aged 25+ and is underpinned by work achieved by IFSBH's working group on ageing.

Discussion: The cost-of-living crisis and cuts to public services risk exacerbating the challenges faced by people with spina bifida and hydrocephalus. Thanks to people's generous donations we continue to be there for them.

Country Update

Sapphire Ballroom | 24 October 2024 | 0855 - 0900 hrs

Country Update: Camps for Children and Young People with Disability

¹Andrej & Terezia Drdul

¹Slovak Association for Spina Bifida and/ or Hydrocephalus, Slovakia

Background: The Slovak Association (SBaH) organizes regular camps to empower independent life for children with spina bifida and hydrocephalus. SBaH started to organize camps 18 years ago. Organisation intended to master self-service skills as the ultimate condition for independent life. Camps are managed in a way children and young people learn to balance physical and mental health. By doing that we believe we positively influence the quality of life. Community teaches young people to take responsibility for each other. Some young people started with us from the very beginning and now they volunteer and share their own experiences with the next generation.

Methods: Regular organization of summer camps and other weekend encounters with children with spina bifida and hydrocephalus. Children with spina bifida are not the subject of medical interest only. They live their childhood, dreams, fears, and hopes. They develop their ability as they grow. Life in a community teaches them among other things social skills. The belief is that social skills are an inevitable condition for independent life.

Findings: It was realized that young people with and without disability if they have a chance to contribute to the groups learn to trust and share. Doing that it was realized that young people feel responsibility for each other and support themselves. The differences in social skills between young people with disability if they grow together with those who are not are enormous. The Association develops and forms volunteers of people with and without disabilities. Doing that the organisation creates their own volunteer sources.

Discussion: The findings are the reason that social skills are crucial for young people with disability to reach an independent life. The association is open to sharing its own property – knowledge and experience gained to encourage Associations across the World to create a regular meaningful time for young people with and without disability where they have the opportunity to learn to grow, trust, and experience vicinity.

Country Update

Sapphire Ballroom | 24 October 2024 | 0900 - 0905 hrs

Country Update: Up Date on Guatemala SB Situation

Mdm Victoria Sandoval Cáceres De Lara

Asociación Guatemalteca de Espina Bífida -AGEB-, Kilómetro 23.5 al Salvador, Condominio Casa y Campo, 2a avenida Lote 28 D, Fraijanes, Guatemala, Guatemala

Background: In Guatemala we have the Guatemalan Spina Bifida Association -AGEB-, which, after a period of crisis, is seeking to excel again. It has been complicated by the issue of the pandemic that left the National Hospitals Network in a very poor condition and therefore the Association without medical healthcare. The pandemic is over but with the political conflicts we have had, it has been difficult to recover the place we previously had.

Methods: As an awareness campaign, we are starting a video-blog project to disseminate information about Spina Bifida. For which we are working on different topics related to EB and its prevention, which will be discussed on social networks, with very simple language so that they can reach people in the most remote places of Guatemala, and if possible from other Spanish-speaking countries, taking advantage of the globalization that social networks allow.

Findings: We have found-out that SB-teenagers thrive when they are able to socialize with other SB-teenagers, so we work on socialization programs that allow young people to lead a socially active life and share their experiences with their pairs.

Discussion: Challenges for 2025:

1. Ensure that the video-blog program reaches people interested in the topic of SB throughout the Republic of Guatemala.
2. Manage to regain the space that the AGEB had in the Guatemalan public health system.
3. Strengthen the group of young adults and make it grow.

Country Update

Sapphire Ballroom | 24 October 2024 | 0910 - 0915 hrs

Country Update: Spina Bifida and Hydrocephalus Association of Malaysia (SIBIAM)

Dr Chua Li-Shun

SIBIAM, Malaysia

SIBIAM is proud to host the 30th International Conference on Spina Bifida and Hydrocephalus (30th ICSBH) in Malaysia, with the theme “Bridging the Healthcare and Prevention Gaps – A Multidisciplinary Team Approach with the Community at Heart”. The conference rounds off a four-year effort to raise awareness about spina bifida and hydrocephalus (SBH) throughout Malaysia, which started with the procurement of the Rotary International Global Grant in 2021. The Global Grant was executed in phases throughout 2021-2023, including seven regional workshops that saw multidisciplinary experts share their knowledge and expertise with local healthcare workers, SBH persons and their care partners. Upon the successful bid for the 30th ICSBH, we have focused our attention on bringing the best to the SBH community and are excited to share our beautiful country with the world. Despite the busy preparations going on, SIBIAM remained an active participant in IFSBH's events in 2024, with contributions to IF's Siblings Day and Parents Day celebrations. The Sarawak SIBIAM support group also held several gatherings, most recently a Family Day event on 31st of August 2024. Currently SIBIAM has a total of 435 members, of which 342 are SBH persons and the rest made up of SBH families/guardians, healthcare workers and other supporters from the general public. As we grow in numbers, we hope to continue building capacity among our members in peer support skills, raising awareness, and making a mark in both the local and international SBH community.

Country Update

Sapphire Ballroom | 24 October 2024 | 0915 - 0920 hrs

Country Update: Spina Bifida in Indonesia: Challenges, Needs, and Sustainability

Primarini, Ayu; Bagis, Wardah; Larasati, Mikhaela

Komunitas Spina Bifida Indonesia, Jakarta, Indonesia

Background: The Komunitas Spina Bifida Indonesia is a spina bifida support group in Indonesia since December 31, 2016. A study was conducted to investigate the prevalence, challenges, and needs of individuals with Spina Bifida in Indonesia, focusing on the disorder's multifactorial etiology and identifying the specific needs of affected individuals. It also explores potential collaborations to improve their quality of life.

Methods: A mixed-methods approach was used, combining quantitative data analysis by a survey and qualitative insights from interviews.

Findings: From the results from a survey study, the results indicated Spina Bifida to be one of the most common congenital disorders, followed by encephalic and anencephaly. The most prevalent types included Lipomyelomeningocele (25.2%) and myelomeningocele (23.7%). Cautious interpretation is needed as national surveillance data in Indonesia is lacking. In addition, the qualitative data from interviews showed several challenges identified by persons with spina bifida and or hydrocephalus living in Indonesia. The frequent reported challenges include: (i) Lack of healthcare facilities and trained medical personnel in remote areas; (ii) Need for comprehensive and accessible medical care guidelines; (iii) Insufficient availability of medical assistive devices; (iv) Lack of psychological support and inclusive educational environments; (v) Need for early training and education on Clean Intermittent Catheterization (CIC).

Discussion: The study concludes that individuals with Spina Bifida in Indonesia face significant challenges requiring comprehensive and sustainable solutions. Improving healthcare facilities and training in remote areas is crucial, alongside developing comprehensive medical care guidelines and increasing the availability of medical assistive devices. Psychological support and inclusive education are essential for enhancing their quality of life. International collaborations with organizations, NGOs, and academic institutions can enhance medical training, provide funding, and facilitate research to develop new interventions. Through these efforts, the quality of life for individuals with Spina Bifida in Indonesia can be significantly improved, enabling them to thrive and contribute to society.

Country Update

Sapphire Ballroom | 24 October 2024 | 0920 - 0925 hrs

Country Update: Australia: Where Are We Now?

¹Duff, Kerrie; ²Thompson, Christine

¹Spina Bifida Community Western Australia, Perth, Australia,

²Spina Bifida Community Western Australia, Perth, Australia

Background: Spina Bifida Associations and support groups have had a long history in Australia, commencing in 1965, with the aim to improve the lives of people living with spina bifida and hydrocephalus through support, advocacy and lobbying.

Methods: Kerrie Duff and Christine Kuca-Thompson undertook research through a written survey and focus groups to update IF about how people with sb/h and their families fared around Australia. It became apparent that individuals are currently relying on their own and ad hoc personal connections.

Findings: Australia lacks a registered SB/H Association although some smaller, informal community groups have re-established themselves. Survey respondents indicate gaps in services that need addressing for people with sb/h and their families to live good lives. The current use of formal, informal, and paid support being utilized reveals a sense of exhaustion and frustration. Few survey respondents have the skills or energy to identify, educate and access the resources needed.

Discussion: From the survey and conversations with people living with sb/h there is a strong need for a new national association to unite Australians living with sb/h in a more systematic and concerted way.

Country Update

Sapphire Ballroom | 24 October 2024 | 0925 - 0930 hrs

Country Update: Out- of -pocket Expenditures of Spina Bifida and Congenital Hydrocephalus Patients Enrolled for Inpatient Treatment and Follow-up at St. Peter Specialized Hospital and Zewditu Memorial Hospital, Addis Ababa Ethiopia

Dr Nebiyat Tesfaye

St Peter Specialized Hospital pediatrics Neurosurgery case coordinator, Addis Ababa Ethiopia.

Collaborators

1. *Dr Hana Muluye, Email hanamuluye1@gmail.com, General Practitioner.*
2. *Dr Bethelehem Yesehak Worku, Email bethelehem.yesehak@aau.edu.et, Assistant professor in Addis Ababa University, College of health sciences, School of Medicine, Department of Surgery, Neurosurgery Unit, Addis Ababa, Ethiopia.*
3. *Dr Kibruysfaw Zewdu, Email-kziberg@gmail.com, Assistant professor in Addis Ababa University, College of health sciences, School of Medicine, Department of Surgery, Neurosurgery Unit.*
4. *Dr Yemisrach Bizuneh Aklilu, Email- yemisirachbizuneh@gmail.com, Assistant professor in Addis Ababa University, Collage of health sciences, School of Medicine, Department of Surgery, Neurosurgery Unit.*
5. *Dr Vijaya Kancherla, Email- vijaya.kancherla@emory.edu, Deputy director of center for Spina-Bifida prevention, Research Assistant Professor, Department of Epidemiology Emory University.*
6. *Dr Marinus Koning, Email- mkoning@reachanother.org , fellow of American college of surgeons.*
7. *Dr Yakob Seman, Email- ahmedys@vcu.edu, Humphrey fellow, Public health policy, VCU.*
8. *Michael Meggabi, Email- mmeggabi@gmail.com, Masters of social work, St peter Specialized Hospital Social Work Department coordinator, Addis Ababa, Ethiopia.*
9. *Dr Girmaye Dinsa, Email- girmaye@gmail.com, Senior Health Economist, Addis Ababa, Ethiopia.*

Background: As of 2018, neural tube defects (NTD) affect between 60 to 170 per 10,000 live births in Ethiopia. Hydrocephalus (HCP) is a NTD comorbidity which affects brain development and requires life-long surgical management. The out-of-pocket expenses for the treatment of these neurosurgical conditions was assessed in two large-volume hospitals in Addis Ababa, Ethiopia.

Methods: A survey-based study of caregivers of newborns with NTD and HCP at Zewditu Memorial Hospital and St. Peter Specialized Hospital was conducted from April 2022 to April 2023. Surveys were administered verbally by a coordinator at hospital admission, one-week follow-up, one-month follow-up, three-month follow-up, and six months after discharge. A modified Harvard questionnaire survey evaluated medical, non-medical and indirect expenditures. Catastrophic Health Expenditure (CHE) was defined as total out-of-pocket expenditure (OOPE) exceeding 10% of the total annual household spending.

Findings: A total of 245 caregivers participated in the study. The median total expenditure of households for treatment was ETB 11,510.00 (\$ 200.94) with the major expense (57.22%) occurring during time of hospitalization and for indirect medical expenditure (56.6%). Forty nine percent of the participants suffered CHE. In multivariate analysis St. Peter's hospital (AOR:8.280, 95%CI: 2.078-33.000, p=0.003), richest wealth quintile households (AOR=0.215; 95%CI=0.057,0.815; p=.024), residency outside of Addis Ababa (AOR:3.259, 95%CI:1.397-7.601, p=0.006) and pre-admission duration of stay more than a week (AOR:5.448, 95%CI:1.171-25.350, p=0.031) were statistically significantly associated with CHE.

Discussion: Our study shows a high-rate of CHE in households with NTD and HCP. Efforts to improve the quality of care at regional hospitals and to reduce the delay in presentation could reduce OOPE. We also advocate for prevention of NTD through fortification with folic acid and supplementation.

Country Update

Sapphire Ballroom | 24 October 2024 | 0930 - 0935 hrs

Country Update: A 25th anniversary of Empowering Filipinos with Spina Bifida

Bolong, D., Mijares, C.

¹SPINA BIFIDA SUPPORT GROUP FOUNDATION, Philippines

Background: SBSGF Celebrated its 25th Founding Anniversary with the theme 25 years of Empowering Filipinos with Spina Bifida. The association recently received 27 new members nationwide (13 from NCR, 4 from Calabarzon, 7 from Central Luzon, 1 from Eastern Visayas, 1 from Central Visayas, 1 from Zamboanga). At the present, the foundation has 341 active members.

Methods: As part of its 25th Founding Anniversary, SBSGF distributed free Pedia wheelchairs to some of its members across the country. This initiative aimed to provide mobility and independence to children with spina bifida ensuring that they can participate fully in their daily activities and live life to the fullest. Moreover, SBSGF hosted an inaugural SPINA BIFIDA PHILIPPINES YOUTH ASSEMBLY, themed “Speak Up! Be Heard! Spina Bifida Youth Matter!”

Findings: In this presentation an overview will be presented on community-based approaches by SBSGF. In particular, the 1st Spina Bifida Youth Assembly in the Philippines served as a platform for participants to voice their concerns, share their life experiences, and emphasize the significance of their voices being heard. The gathering facilitated meaningful discussions, contributing to

Discussion: The SBSGF provides its members with important resources and opportunities to build capacity. To strengthening the collaboration with the partners both locally and regionally, future plans for organising the next meeting of the SBSGF will be shared.

Plenary Abstract

Sapphire Ballroom | 24 October 2024 | 1115 - 1145 hrs

Plenary 1:

A Practical Approach to the Genetics of Neural Tube Defects

Prof Dr Eduardo Tizzano

Department of Clinical and Molecular Genetics University Hospital Vall d'Hebron, Medicine Genetics Research Group (VHIR), Barcelona, Spain

Neural Tube Defects (NTDs) are the most prevalent serious birth defect of brain and spine that occur during human development characterized by failure of the neural tube to close, resulting in various severities of malformations. NTD pathogenesis is not fully understood although genetic and environmental factors play an essential role in the mechanisms of NTDs. Indeed, folate deficiency during pregnancy is the most known categorical “environmental” factor predisposing to develop a NTD. However, to date, no major Mendelian “NTD genes” have been identified in humans. Indeed, in most cases, the pattern of inheritance and recurrence risk in families is multifactorial without following Mendelian laws. The majority of NTD cases are non-syndromic, meaning the feature of the respective NTD is the only defect and not just one feature of an identified syndrome. However, around 10% occur as part of a syndrome with known genetic etiology with syndromic or chromosomal abnormalities. Since NTD's are within the most common congenital malformations in humans, several aspects need to be addressed in the communication of the diagnosis and possible genetic testing. With the advances in next generation sequencing candidate genes can be studied and genetic counselling adequately provided for better understanding of the impact in the family, recurrence risks and long-term management.

Sapphire Ballroom | 24 October 2024 | 1205 - 1225 hrs

Plenary 3:

Building a Multidisciplinary Team and Why This Matters

Dr Erin McNamara

Pediatric Urology

*Director of Spina Bifida and Congenital Spinal Anomalies Center
Boston Children's Hospital, Department of Urology, USA*

Spina bifida necessitates comprehensive management involving various medical specialties. As the director of our spina bifida team, I recognize the importance of establishing a strong multidisciplinary approach in delivering optimal care. Our team comprises pediatric urologists, neurosurgeons, orthopedic surgeons, nephrologists, complex care pediatricians, nurses, neuropsychologists, social workers, and other key stakeholders. Working collaboratively, we address urological, neurological, orthopedic, renal, psychological, and social aspects of spina bifida. Benefits of a multidisciplinary approach include holistic assessment, early identification of complications, streamlined treatment, reduced fragmented care, and prevention of errors. Communication within our team allows for close monitoring and prompt resolution of concerns. Our team has observed improved patient outcomes since adopting a multidisciplinary approach, including enhanced patient satisfaction, reduced hospitalizations, optimal continence outcomes, and improved psychosocial well-being. In conclusion, building a multidisciplinary team is vital for comprehensive care in spina bifida. By pooling our expertise, we can optimize patient outcomes and improve quality of life for those living with spina bifida.

Plenary Abstract

Sapphire Ballroom | 25 October 2024 | 0900 - 1000 hrs

Plenary 5: Advocacy for Disability Inclusion

Dato' Dr Amar-Singh HSS

Consultant Paediatrician, Child-disability Activist

Advisor, National Early Childhood Intervention Council (NECIC)

Honorary Senior Fellow, Galen Centre for Health and Social Policy

Malaysia

Advocacy for disability inclusion is a call for social justice and human dignity. It recognizes inclusion as a universal human right, essential for dignity and worth of every individual, crucial for being accepted as we are. This advocacy highlights the necessity of removing barriers -- legal, policy-based, institutional, or attitudinal -- that hinder the full participation of persons with disabilities (PWDs) in society.

The journey towards inclusion aims to provide equal access and opportunities to all, without discrimination. It redefines citizenship beyond the possession of an identity card to active and full participation in nation-building. However, the reality for many PWDs is starkly different. They face significant challenges in achieving full inclusion in education, employment, housing, healthcare, transportation. The prevalent view of disability as a tragedy perpetuates a charity model, where PWDs are seen as lesser beings, leading to their marginalization and mockery.

Advocating for disability inclusion means challenging this status quo and acknowledging that inaction contributes to increasing marginalization of PWDs. It's a fight to ensure that every person, including the disabled community, live as full members of society. This advocacy is not just about policies and programmes, but about transforming societal attitudes and behaviors to embrace diversity and foster a truly inclusive community.

Sapphire Ballroom | 26 October 2024 | 0830 - 0900 hrs

Plenary 6: Trial and Tribulations of Transition Care

Dr Erin McNamara

Pediatric Urology

Director of Spina Bifida and Congenital Spinal Anomalies Center

Boston Children's Hospital, Department of Urology, USA

This presentation aims to address the trials and tribulations encountered during the transition period. The talk will explore the psychological, social, and medical aspects that demand attention and coordination.

The presentation will highlight the multifaceted challenges faced by patients, families, and healthcare providers, with a focus on overcoming barriers to successful transition. Strategies for fostering patient engagement, promoting self-management skills, and utilizing shared decision-making will be discussed. Real-life case studies will be used to illustrate the complexities of this process.

In addition, the talk will cover interventions and protocols that can facilitate a smooth transition, including transition clinics, care coordination systems, and the integration of technology into healthcare delivery. The importance of interdisciplinary collaboration and the involvement of different specialists will also be emphasized.

By analyzing the trials and tribulations of transition care in spina bifida, this presentation aims to provide practical knowledge and tools to enhance the transition care experience. Through proactive measures and dedicated support, patients, caregivers, and healthcare providers can successfully navigate this critical phase.

Plenary Abstract

Sapphire Ballroom | 26 October 2024 | 0900 - 0930 hrs

Plenary 7: Quality of Life and Ageing with Spina Bifida

Prof Dr Amaramalar Selvi Naicker

*Dept of Orthopedics, Faculty of Medicine,
Hospital Canselor Tunku Muhriz. University Kebangsaan,
Malaysia*

Spina bifida (SB) and hydrocephalus are common congenital anomalies caused by disruptions in neural tube development. Declining incidences in some regions are linked to increased public awareness, folic acid supplementation, and improvements in prenatal and postnatal care. Advances in multidisciplinary care have also led to better functional outcomes and quality of life (QOL) for individuals with SB.

While children with SB face challenges like mobility issues, incontinence, hydrocephalus, and cognitive impairments, adults encounter additional complications such as shunt malfunctions, syringomyelia, and musculoskeletal pain. Older adults also deal with neuromuscular weakness, neurogenic bladder, and skeletal deformities, contributing to reduced independence and functionality.

Moreover, emotional and psychological difficulties, such as anxiety, depression, low self-esteem, and social isolation, are prevalent among adults with SB. These issues stem from the visible nature of their disabilities, reliance on assistive devices, and challenges in social participation. Adults with SB often experience loneliness, difficulty maintaining employment, and dependence on caregivers, affecting their mental well-being.

Managing the aging SB population requires a comprehensive approach that prioritizes both physical and emotional aspects of care, ensuring better QOL and promoting social integration to mitigate the long-term impact of the disease.

Roundtable Discussion Abstract

Sapphire Ballroom | 24 October 2024 | 1400 - 1430 hrs

Roundtable Discussion I

Facing a Pregnancy with a Neural Tube Defect: A Cascade of Communications and Shared Decision Making

Objective/Aim:

To discuss all the alternatives and challenges faced by parents of a pregnancy in which an open NTD was diagnosed. This involves communicating the diagnosis, obtaining information from different specialists understanding possibilities from prevention to treatment, and taking into account the principle of autonomy of the parents and possible outcomes.

Emerald Room | 25 October 2024 | 1030 - 1110 hrs

Roundtable Discussion II

Transition from Paediatric to Adulthood: When the Voice of the Patient is Becoming More Important than the Voice of the Parents.

Objective/Aim:

To discuss the different protagonist and factors involved in the transition from childhood-adolescence-adult life. Multidisciplinary paediatric care is effective during childhood and creates an important link between the patient, families, and the different specialists. As patients grow into adolescence principles of autonomy start to begin and in most of the healthcare systems there should be a change from paediatric to adult specialists. The transition is a process that involves both groups of specialists during late adolescence in order to help the patient and the families to face this change.

Forum Abstract

Emerald Room | 25 October 2024 | 1110 - 1240 hrs

Youth Forum: Stronger Together

Type: Parallel session organised for and by youth with Spina Bifida and Hydrocephalus (SBH)

Theme: Youth Sharing Experiences about Living with SBH in Terms of Mental Health

Moderators: Kateryna Shcherbyna (Brussels) & Nebiyat Tesfaye (Ethiopia)

Participants: All youth living with SBH are welcomed for this session

Age Range: 18-35 years

Location: Separate Room at Conference Venue

Duration: 1.5 Hours

Session Objectives:

1. Create a supportive space for youth with SBH to connect and share experiences.
2. Facilitate discussions on key issues such as mental health, healthcare access, and quality of life.
3. Collaboratively define priorities for youth advocacy and awareness in the SBH community.

Program Outline

1. Introduction (10 minutes):

- Introduction by the moderators Kateryna and Nebiyat
- Introduction theme of the session through personal stories on lived experiences with a focus on mental health and overcoming challenges;
- Set the tone for open, supportive, and honest conversation;

2. Round Table Discussion (45 minutes):

Moderators invite participants to share their experiences. Suggested prompts:

- How has SBH impacted your mental health?
- How accessible is healthcare in your city/country?
- What do you perceive as your biggest challenges, and how do you cope?
- Encourage participants to listen to each other's stories, fostering connection and empathy.

3. Defining Priorities Together (20 minutes):

- During this interactive segment, participants elaborate in defining key priority areas for youth with SBH around the world;
- Priorities will be defined for the areas of youth advocacy, mental health support, and healthcare improvements;
- An action plan will be created including key recommendations and actionable goals for participants which can also be shared with the overall participants of the conference;

4. Wrap-Up and Closing (15 minutes):

- A summary will be provided including the key points discussed and the priorities identified;
- Moderators will share guidance and tools on how participants can further engage in raising awareness, engaging in advocacy, and building support networks;
- An empowering message will be shared, encouraging youth to stay connected and continue supporting one another beyond the session.

Outcome:

Participants will leave with a sense of community, clarity on key issues affecting youth with SBH, and motivation to advocate for change both individually and collectively.

Forum Abstract

Sapphire Ballroom | 26 October 2024 | 1120 - 1150 hrs

Advancing Understanding on Urological and Mental Health Needs in an Ageing SBH Community

Names: *Kevin O'Donnell (Chair; Spina Bifida Hydrocephalus Scotland), Gerry Maguire (Spina Bifida and Hydrocephalus Ireland), Mario Sel (Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw, Belgium), Teije Dijk (Spina Bifida en Hydrocephalus Nederland, The Netherlands), Eva Toft (Spin-Off, Sweden), Jon Bateman (Individual member from Southern Alberta, Canada), and Chetan Shoraff (Spina Bifida Foundation India), Burhan Elli (Spina Bifida Derne i Turkey), and Jyoti Fernandes (Spina Bifida Foundation India).*

Background: Due to improved care many individuals with SBH have reached adulthood. However, there is a significant gap in our knowledge regarding the physiological, cognitive, and independence challenges they face. Therefore, the topic of ageing is important for the SBH community. Previously, the IF Working Group on Ageing with SBH published a report on best practice example programmes and interventions to meet the needs of the ageing SBH community. Subsequent activities revealed the much needed work on mental health. In follow up, steps were taken to unfold urological and mental health needs in an ageing SBH community. Particularly, topics which will be highlighted include incontinence management and the interplay between mental and physical health concerns among ageing SBH individuals.

Methods: Significant contributions are needed to improve quality of life in an ageing SBH community. The IF Working Group on Ageing with SBH orchestrated initiatives centred around the areas of urological management and mental health. These included knowledge sharing activities, awareness raising, participation in key high level events, and producing publications and reports.

Results: The perspectives of older persons with SBH on urological and mental health needs will be shared. Moreover, the findings of the different knowledge gathering activities by the IF Working Group on Ageing with SBH will be shared.

Conclusion: It is imperative to improve the understanding of lived experiences of older persons with SBH. For this reason, the IF Working Group on Ageing with SBH will continue to undertake efforts to shed light on the often overlooked yet critical aspect of urological management and mental health within the ageing SBH community.

Speaker Abstract

Sapphire Ballroom | 25 October 2024 | 1110 - 1130 hrs

Early Bladder Management in Neurogenic Bladder - How to Evaluate and How to Manage

Dr Erin McNamara

Pediatric Urology

Director of Spina Bifida and Congenital Spinal Anomalies Center

Boston Children's Hospital, Department of Urology, USA

Early bladder management is essential in the neurogenic bladder of pediatric patients with spina bifida. As a pediatric urologist and director of a spina bifida team, this talk highlights the importance of proactive care in evaluating and managing bladder function. Urodynamics and imaging techniques play critical roles in evaluating bladder function.

Urodynamic studies identify detrusor overactivity, sphincteric dysfunction, and bladder compliance. Imaging, such as renal ultrasound and voiding cystourethrogram, detects structural abnormalities and assesses upper urinary tract function. Proactive management includes early clean intermittent catheterization initiation, anticholinergic therapy, and

In conclusion, early bladder management in the neurogenic bladder is crucial. This talk underscores the significance of proactive care, utilizing urodynamics and imaging, for long-term bladder health and overall well-being in spina bifida patients.

Sapphire Ballroom | 25 October 2024 | 1150 - 1210 hrs

Engineered/Fusion Toxins for Treatment of Neurogenic Bladder Dysfunction

Dr Hatim Thaker

Boston Children's Hospital/Harvard Medical School, Boston, Massachusetts, USA

Onabotulinum toxin A, or Botox, is used as a third-line therapeutic agent for patients with neurogenic bladder dysfunction secondary to spina bifida. This medication is approved for use in children. Over the past 10-15 years, clinical trials have updated the injection techniques in order to improve outcomes. This talk will discuss the nuances of Botox injection for treatment of neurogenic bladder. In addition, preliminary data on next generation toxins that are specific for the neurogenic bladder dysfunction will be revealed.

Speaker Abstract

Sapphire Ballroom | 25 October 2024 | 1210 - 1240 hrs

Innovative Multidisciplinary Approach to Developing Clinical Practice Guidelines for Neurogenic Bladder Management in Children and Adolescents: A Collaborative Endeavor

Prof Dr Christian Radmayr

Introduction: Neurogenic bladder in children and adolescents presents complex challenges requiring comprehensive management strategies. Traditional guideline development often lacks input from diverse stakeholders, potentially overlooking crucial aspects of care. We present a novel approach to guideline development that integrates perspectives from pediatric urologists, nephrologists, psychiatrists, and patient representatives.

Methods: A multidisciplinary team comprising specialists in pediatric urology, nephrology, psychiatry, and patient advocates collaborated to develop clinical practice guidelines for neurogenic bladder management in children and adolescents. The process involved systematic literature review, consensus-building exercises, and iterative revisions based on stakeholder feedback.

Results: The collaborative effort yielded comprehensive clinical practice guidelines that address the multifaceted nature of neurogenic bladder management. Key recommendations encompassed medical interventions, psychosocial support, and patient-centered care principles. The guidelines emphasize the importance of individualized treatment plans tailored to patients' unique needs and preferences.

Conclusion: This innovative approach to guideline development represents a significant advancement in the field of pediatric urology and other specialties involved in the management of spinal dysraphism. By integrating diverse perspectives and prioritizing patient involvement, the resulting guidelines are poised to enhance the quality of care for children and adolescents with neurogenic bladder. Presentation of these findings at a global meeting offers an opportunity to share insights, foster dialogue, and promote the adoption of multidisciplinary approaches in clinical practice.

Sapphire Ballroom | 25 October 2024 | 1430 - 1450 hrs

POO Power: Developing a Logical Framework and Network for Managing Neurogenic Bowel

Dr Tan Yew Wei

Department of Surgery (Paediatric Surgery), Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia

Neurogenic bowel dysfunction, particularly in patients with spina bifida (SB), poses significant challenges, often manifesting as chronic constipation and incontinence. These issues not only compromise physical health but also impact social wellbeing due to the stigma associated with incontinence, affecting both patients and their families. Despite the prevalence of neurogenic bowel issues, bowel management remains under-practised globally, creating a void in care pathways. At Universiti Malaya, we have pioneered a scientific and logical bowel management programme, focused on achieving social cleanliness and improving quality of life. This presentation introduces the POO (Professionalism, Openness, and Oneness) Power framework to address these challenges. Using a "hub and spoke" model, we propose centralising bowel management care with outreach systems to ensure accessible and consistent care. Professionalism is essential in upskilling healthcare providers and educating patients and caregivers, while openness fosters transparent communication across all levels—engaging care homes, hospitals, and key stakeholders to push for improved resources and funding. Through examples of how enhanced knowledge-sharing and technology can drive change, I will outline a vision for a cohesive network that supports patients with SB in achieving better health outcomes and social integration.

Speaker Abstract

Sapphire Ballroom | 25 October 2024 | 1510 - 1530 hrs

Bridging the Gap: Collaborative Care from Hospital to Home for SBH Patients

Assoc Prof Dr Tan Chai Eng

Department of Family Medicine, Faculty of Medicine, Universiti Kebangsaan Malaysia, Kuala Lumpur, Malaysia

People living with spina bifida and/or hydrocephalus have various healthcare needs and concerns that require long-term care from a multidisciplinary team. Care coordination is important to ensure seamless care from hospital to home, as well as from childhood to adulthood. The care coordination process begins from conducting a holistic needs assessment, formulating both short-term and long-term care plans, identifying and communicating with relevant care providers, and maintaining a working collaboration for the care of the individual with SBH. Community-based healthcare providers including primary care providers lack experience and knowledge regarding care for SBH patients. They would benefit from training, guidelines and guided individual management plans from the primary team to assist them with long term care for people with SBH. Having a formal communication channel and appropriate clinical information sharing between the primary team and community team is necessary to ensure proper coordination of care across different settings. Integrated care pathways should be developed together with relevant disciplines and care providers to assist in ensuring important steps are not missed in care provision and facilitate a seamless transition between hospital and community-based care. Promoting inter-disciplinary and inter-professional collaboration is essential to support people living with SBH and their families.

Emerald Room | 25 October 2024 | 1450 - 1510 hrs

Robotic Surgery in Patients with Spina Bifida

Dr Hatim Thaker

Boston Children's Hospital/Harvard Medical School, Boston, Massachusetts, USA

Surgical treatment for patients with neurogenic bladder dysfunction secondary is often necessary to protect renal health, improve bladder capacity and pressure, as well as achieve urinary continence. Classically, reconstructive surgery for neurogenic bladder has been performed through open surgical techniques. With the advancement of endoscopic and robotic surgical systems, these surgeries can now be performed through a minimally invasive approach. This talk will review the endoscopic treatment options for urinary incontinence, and discuss the robotic assisted laparoscopic surgical techniques for Mitrofanoff and MACE formation, bladder neck reconstruction, and many other procedures.

Speaker Abstract

Sapphire Ballroom | 26 October 2024 | 0930 - 0950 hrs

Common Musculoskeletal Problems In Spina Bifida - Rehabilitation Approach

Prof Dr Rashidah Ismail @ Ohnmar Htwe

Senior Consultant Rehabilitation Medicine Physician

Department of Orthopaedics and Traumatology

Faculty of Medicine, Universiti Sultan Zainal Abidin (UniSZA)

Spina bifida, a congenital neural tube defect, often leads to significant musculoskeletal problems due to neurological impairment and altered biomechanics. Common musculoskeletal issues include scoliosis, hip dislocation, lower limb deformities, osteopenia, osteoporosis and fractures, which can severely impact mobility and quality of life. The rehabilitation approach for individuals with spina bifida is multifaceted, encompassing physical therapy, occupational therapy, orthotic intervention, and surgical options. Early intervention is crucial for optimizing functional outcomes, focusing on strengthening exercises, gait training, and postural alignment. Orthotic devices play a vital role in enhancing mobility and stability, while surgical interventions may be necessary for severe deformities.

Multidisciplinary teams, including rehabilitation medicine physicians, paediatricians, orthopedic surgeons, physiotherapists, occupational therapists, orthotists, prosthetists and psychologists, collaborate to create individualized rehabilitation plans that address the unique challenges faced by each patient. Additionally, ongoing assessment and adaptation of interventions are essential to accommodate growth and changes in functional abilities. This comprehensive approach not only aims to improve physical function but also to enhance psychosocial well-being, participation in daily activities and improve quality of life.

Speaker Abstract

Sapphire Ballroom | 26 October 2024 | 0950 - 1010 hrs

Orthopaedic Management in Spina Bifida

Dr Matthias Axt

The Children's Hospital at Westmead, Sydney Children's Hospitals Network, Australia

Spina bifida refers to a failure of the neural tube to close (neurulation defect) or to further differentiate (post-neurulation defect). Orthopaedically relevant entities for both periods include myelomeningocele, lipomeningocele, diastematomyelia and caudal regression syndrome. Spina bifida leads to symmetrical or asymmetrical paraplegia/muscle weakness at and below the affected level plus lack of sensation. Associated Arnold Chiari malformation affects intellectual development, balance and orientation in space which can limit the child's function and orthopaedic management.

Depending on the neurological level children may have hip and knee flexion contractures, dislocated hips, and foot deformities like talipes equinovarus, congenital vertical talus, cavus foot deformities and calcano-valgus deformities. Development of scoliosis is common. Children affected at thoracic level often have a kyphosis/gibbus causing pressure sores in the wheelchair. Predictors for a child to become a community ambulator are quadriceps function of 4/5 strength (level L3 and below) and sitting balance.

Principles of Orthopaedic management: Every child should stand/walk, starting between 18 and 24 months, when the child has good sitting balance and when the child pulls himself up to stand. Temporary verticalization/walking at thoracic and high lumbar level is common practice. Over 40% will use a wheelchair long-term. Most children need orthotic management, stabilising ankle (AFOs), knee (KAFOs), hip (HKAFOs) and thoracic (reciprocal gait orthosis) levels.

Orthopaedic surgery aims at aligning all lower limb joints via anterior hip, posterior knee and foot releases, guided growth to distal femur, distal femur extension osteotomies, followed by bracing. Dislocated hips are usually left alone. Scoliosis surgery indicated if curve over 45 and sitting balance is poor. Gibbus resection indicated to treat/prevent pressure ulcers. Regularly monitor: motor/sensory function, skin, ROM of all joints, mobility, orthoses, spinal deformities.

ART EXHIBITION

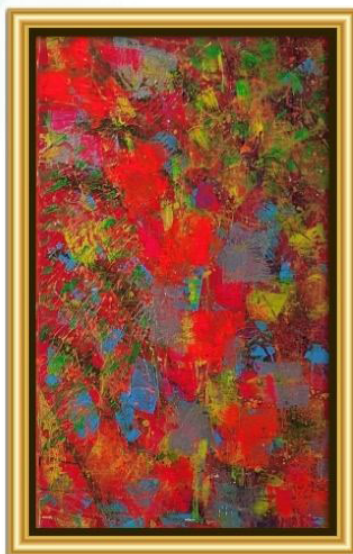
by Aveena K. Devi aka Shakti D

K. Aveena Devi is a mixed media artist, author & motivational speaker. Born with a birth defect called Spina Bifida, Aveena's journey as a differently able has always been challenging from her complex medical condition to her life in general. The constant obstacles she faced with school life and public's patronising & constant misperception about her, only motivated her to bring more positive changes for the differently able community. Therefore she started advocating for inclusivity through speaking engagements, panel sessions counseling. She even became a model under a modeling agency just for the differently able to break the stigma of beauty standards in the media world. She's currently been certified as a Neuro Linguistic Therapist and is working towards bringing all her skills together to build a more inclusive community



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ART EXHIBITION

by Bernadeta Septiana Dwi Krismawati

Bernadeta Septiana, originally from Yogyakarta, Indonesia, balances her 9-5 job with her passion for painting while living in Malaysia. Her art is deeply connected to her emotions, reflecting her mood at the time of creation.

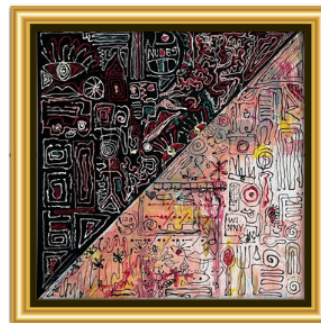
Bernadeta has explored various artistic techniques, from sketching and pouring painting to oil painting, but has ultimately found her artistic voice in acrylic painting. She has a fondness for green olives and burnt orange, colors that remind her of old trees, wisdom, warmth, earthy energy, and coziness. Her works are always infused with vibrant colors, which first take shape in her imagination before coming to life on the canvas.



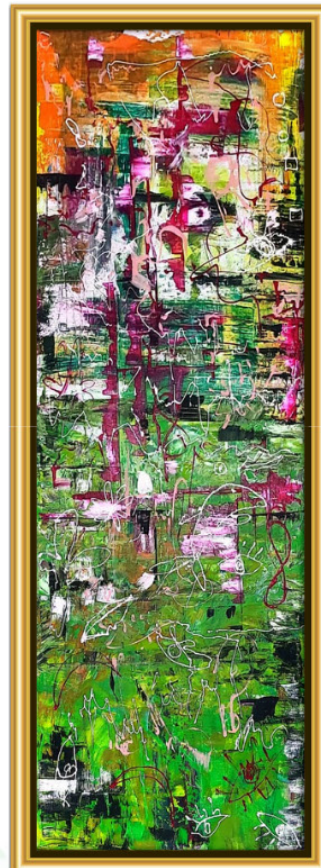
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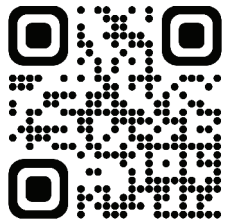
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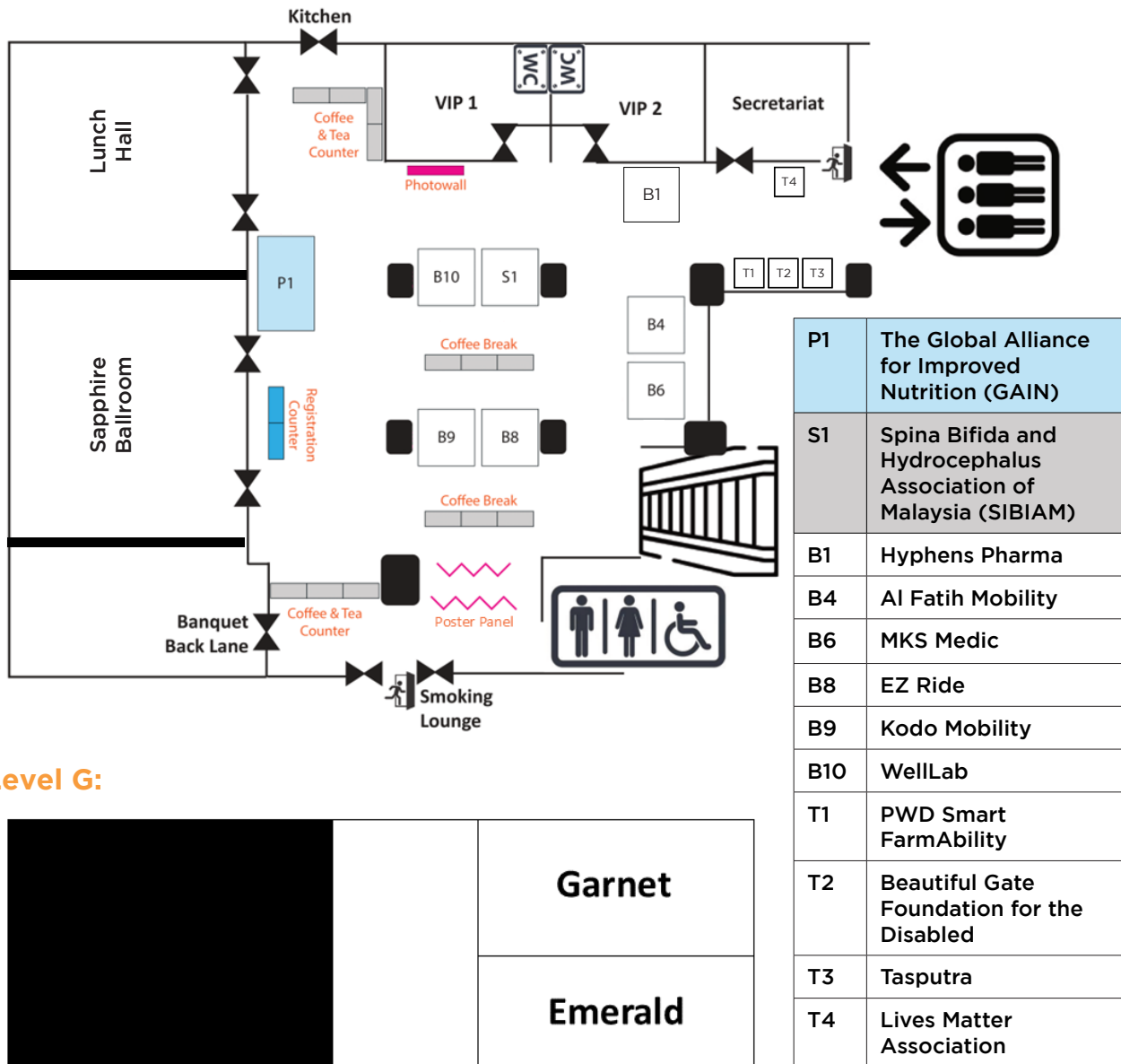


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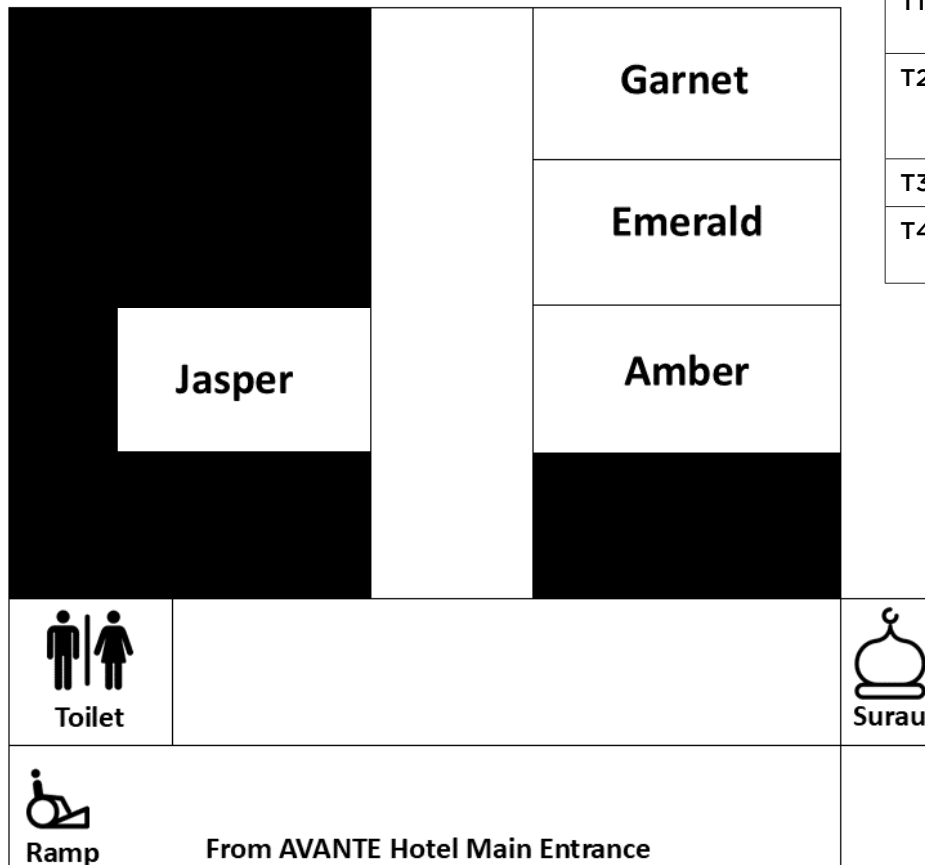
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