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- International Pediatric Association (IPA)

The **Berita MPA** is published for members to keep them informed of the activities of the Association and to keep up with developments in paediatrics and child health.

The views and opinions in all the articles are entirely those of the authors unless otherwise specified.

We invite articles and feedback from readers – Editor <editor.bmpa@gmail.com>

40th Congress in Ipoh

“Marginalised Children - Addressing the Needs”

5-8 September 2018



Our 40th MPA Congress will be at the new Ipoh Convention Centre in Perak. The theme will be on Marginalised Children - Addressing the Needs, identifying the gaps & the way forward.

What exactly are Marginalised Children? These are small groups of children within the population who are usually invisible to people and often not well taken care of. Among these are the disabled (physically and mentally challenged), street children, the stateless, homeless, immigrants, refugees. As an extension, they also include HIV-infected children, autistics, children with rare diseases, children in conflict regions and disaster areas, and the list goes on...

Being marginalised and in the blind spot of society, these children are deprived of a normal childhood, they grow up lacking confidence and may easily end up on the wrong side of the law. There is also a scarcity of data and statistics that are easily accessed. We hope that we can get some additional information and data to help with advocacy work in these areas.

Speakers with different backgrounds

This congress will have speakers who are actually working on the ground with these underserved and underprivileged children. They will not be confined to paediatricians, doctors and medical personnel

continued on page 3...



Group Photo



Seminar for Healthcare Personnel, by Dr Selvakumar (pediatrician HTAA, left) and Assoc Prof Mr Mohd Shukrimi bin Awang (paediatric orthopaedic surgeon IIUMMC, right)

East Coast Spina Bifida Awareness Day 2018

14 April 2018, Kuantan

The Spina Bifida Association of Malaysia (SIBIAM) organised the first East Coast Spina Bifida Awareness Day 2018 on 14 April 2018 in collaboration with the Rehabilitation Medicine Unit, Dept of Orthopedics & Traumatology PPUKM, Rehabilitation Medicine and Paediatric Department of Hospital Tengku Ampuan Afzan (HTAA), Paediatric Department of International Islamic University Malaysia Medical Centre (IIUMMC) and the Rotary Club Damansara. The event was held at the International Islamic University Malaysia Medical Centre and was a resounding success with a total of 320 participants from Pahang, Kelantan, Terengganu and Kuala Lumpur. This included 26 patients with spina bifida and sacral agenesis, 79 family members, 139 health care personnel, 3 VVIPs, 3 visiting speakers and 70 volunteers.

The event started with a Meet & Greet session where **Dr Yang Mee Eng** (President of SIBIAM), **Prof Dr Amara Naicker Naysaduray** (Vice President of SIBIAM) and **Ir Dr Kribanandan G N** (Secretary of SIBIAM) set the scene for the event. They shared the background to SIBIAM and how the organization was established and developed since 2007, provided an overview of the Significant Medical Impacts that Spina Bifida (SB) patients are faced with and highlighted the importance of linkages which have to be made with other organisations to strengthen the level of services and support which can be provided to SB families in need. The session closed with the formation of a Protem committee of interested individuals

who volunteered to serve to build a local network of support for SB patients and their families for the East coast region.

Opening ceremony

This was followed by an opening ceremony where Dr Yang provided an overview of SIBIAM and what had been achieved in the last decade. She inspired those present on how and what she did to overcome her struggles. She credited those who supported her throughout her life and in this context she said it is very important that a branch of SIBIAM be opened in the East Coast of Peninsular Malaysia as members supporting each other as a group will be a great comfort to parents and caregivers. Dr Shaari bin Ngadiman (Pegawai Kesihatan Negeri Pahang) the guest of honour then delivered a poignant speech about the importance of the event and how keen he was to see the linkages made between the health professionals, patients and the support groups like SIBIAM to move the SB agenda in the East Coast. He also suggested setting-up support teams consisting of parents of spina bifida as part of the support program in Pahang. He provided an in-depth account of funding windows which could be tapped into and made available for SB patients and their Care Givers. A walk through to the main foyer was then undertaken to see the Vendors who had set up stalls, and also to visit the SIBIAM booth just before tea break.

The conference programme consisted of three streams, namely activities for health care

professionals, where scientific content on SB was presented, activities for Parents and Caregivers included talks on prevention and management of complications of spina bifida, followed by therapy demonstration by the occupational therapists and physiotherapists. Meanwhile, there was also a parallel fun filled program of entertainment to occupy the SB children so that parents and caregivers could participate fully in the conference.

Emotional sharing session

At the final session of the conference, there was a moving sharing session where we were given a rare insight into the experiences of care givers, parents and Individuals with SB, relating the challenges of raising an SB child or living with SB.

The day ended with closing remarks from Prof Dr Amara and Presentation of certificates and gifts to the attending families and a warm show of thanks to the HTAA team led by Dr Yusma who steered the whole day of activities without a hitch.

We would like to thank Dover Elevators Sdn. Bhd and Latimer Corporation Sdn. Bhd. for their generous financial support for this event. ☐

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