

EVENT SUMMARY East Coast Spina Bifida Awareness Day 2018: 'Educate to Elevate'

The Spina Bifida Association of Malaysia (SIBIAM) organized the first “East Coast Spina Bifida Awareness Day 2018” on 14th 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 (see Table 1).

The event started with a meet and 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 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.

Table 1 List of Participants

| Participants | Number |
|--|---|
| Patients (spina bifida and sacral agenesis) | 26 (15 from Pahang, 10 from Terengganu, 1 from Kuala Lumpur) |
| Parents and family members | 79 |
| Health care personnel (medical officers, staff nurses, physiotherapists, occupational therapists and medical students) | 139 (from Pahang, Kelantan, Terengganu and Kuala Lumpur) |
| VVIPs | 3 <ul style="list-style-type: none"> • Dr Shaa’ri bin Ngadiman (Pengarah Kesihatan Negeri Pahang) • Dr Norazmi bin Abdullah (Pengarah HTAA) • Prof Datuk Dr Mohamed Saufi Bin Awang (Timbalan Pengarah IIUMMC) |
| Visiting speakers | 3 <ul style="list-style-type: none"> • Dr Selvakumar (pediatrician HTAA) • Mr Mohd Aidil bin Mohd Nor (neurosurgeon HTAA) • Assoc. Prof Mr Shukrimi paediatric orthopedic surgeon IIUMMC) |

| | |
|--------------|---|
| Volunteers | 70 <ul style="list-style-type: none"> Specialist, Medical Officers, Staff Nurses, Occupational Therapists, Physiotherapists and PPK (Rehabilitation med department HTAA Paediatric department IIUMMC) SIBIAM members Rotary club members |
| Total | 320 |

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 Shaa'ri bin Ngadiman (Pengarah 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 3 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.

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.

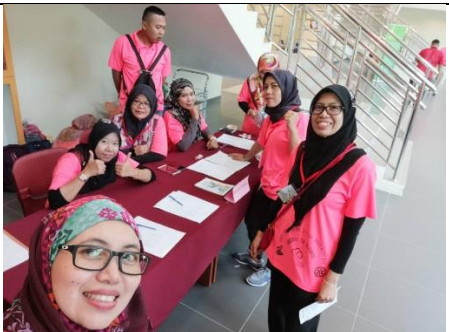

We would like to thank Dover Elevators Sdn. Bhd and Latimer Corporation Sdn. Bhd. for their generous financial support for this event.

Table 2 Programme List and Topics Discussed

| Activities for healthcare personnel | Activities for parents/caregivers/teachers/JKM representatives | Activities for children |
|--|---|-------------------------|
| Meet and Greet Session | | |
| Opening Ceremony | | |
| Overview, Detection and Prevention of Spina Bifida | Introduction to SIBIAM | Sand Art |
| Early Neurosurgical Interventions | Spina Bifida and Its complications, Prevention and management Review of Equipment Needs | Clown and Balloons |
| Musculoskeletal Complications, Rehabilitation Management and Review of Equipment Needs | Management of Neurogenic Bowel and Bladder | Games |
| Orthopaedic Interventions | Occupational Therapy and Physiotherapy Management | |
| Management of Neurogenic Bowel and Bladder | | |
| Role of Physiotherapist and Occupational Therapist | | |
| Sharing Session by Spina Bifida Patients | | |
| Showcase of Equipment by Vendor Company | | |
| Closing Ceremony | | |

The full 1-day conference and sharing was captured with photos as given in Table 3 below.

Table 3 Photographic Record of the Conference

| Programmes | Photos |
|--------------|--|
| Registration |   |

| | |
|------------------------|---|
| |  |
| Meet and Greet Session |     |
| Opening Ceremony |     |

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|---|---|
| |     |
| Workshops and Seminars for Healthcare Personnel |   |
| Workshops and Seminars for Parents/Caregivers |     |

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|-----------------------|---|
| |   |
| Children's Activities |     |
| SIBIAM Booth |     |

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|------------------|--|
| Vendor Booth |   |
| Lunch is Served |   |
| Sharing Session |   |
| Closing Ceremony |   |

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|---------|--|
| |   |
| General |        |