

# By your side... always

## Secretary's Report for the 10<sup>th</sup> AGM



## We have as members SB Patients who are at various ages including adults doing their best to lead active lives

# Formed in 2007



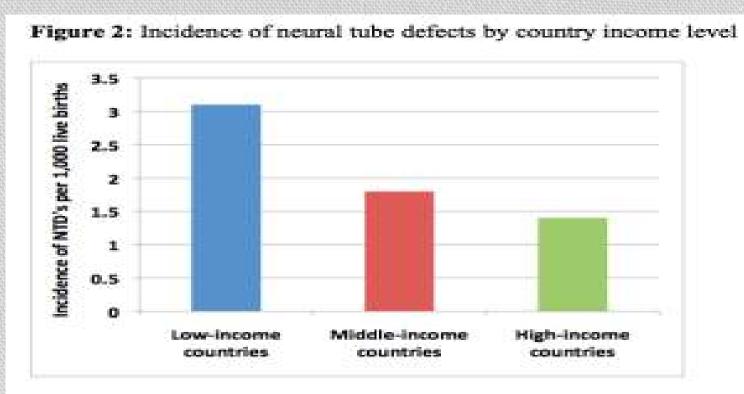






# Incidence

Based on a rate of 1 to 1.5 % of the population with Spina bifida in Middle-Income countries, the estimated Incidence of SB in Malaysia is ~30,000 to 45,000



Data are from Christianson et al.4

# SIBIAM Committee 2016

### > Dr. Yang Mee Eng

Pengerusi/ Chairman

## Prof Dr Amara Naicker

Timbalan Pengerusi/ Vice Chairman

Ir Dr Kribanandan G N

Setiausaha/ Secretary

## En. Nazri Bin Mohamed Rasdi

Timbalan Setiausaha/Asst. Secretary

### Francis Arulandam

Bendahari/ Treasurer

## Lt. Col Selvaraja

Timbalan Bendahari/ Asst Treasurer

# Ahli Jawatankuasa/ Committee members:

- Dr. Yasmin Osman
- En. Hairol Bin Talib
- Ms. Rani Krishaveni
- Mr. Kenneth D'cruz
- Ms. Aini binti Salamat
- Ms. Susan Joseph

# Juruaudit Dalaman/ Internal Auditors:

Steven Gan Eng Huat & Jyan Kothari

## **Past and Present Activities**

## Family Day Sunway 2011















## **Laptop Presentation**











## BNI/ Media Concept Focus to Ng Phooi Ling





## **Christmas Gathering with RCD - Dec 2012**









## **Christmas Gathering - December 2012**









## **Christmas Gathering RCD - December 2012**





# **CONCERT 2013**

"Tribute to Yao Min – Chronicle of Splendour II" November 2013 (RM 40,000 was raised)

## SIBIAM Fund Raising Concert 2013 "Tribute to Yao Min – Chronicle of Splendour II"



## SIBIAM Fund Raising Concert 2013 "Tribute to Yao Min – Chronicle of Splendour II"



## Family Day January 2014







## Family Day January 2014



## Family Day + Christmas Day Dec 2014







### Bukit Kiara Equestrian Club 14<sup>th</sup> of December 2014

## Family Day + Christmas Day Dec 2014



## **SIBIAM Home Visit by Dr. Yasmin's Team**

Home Visit : Angela S Francis' House
Place : No 449 – ½ Batu 2, Jalan
Limbongan, 75200 Melaka.
Date : 26 / 9 / 2014

## **SIBIAM Home Visit by Dr. Yasmin's Team**



Home Visit : Mariamah's House
Place : No. 17, Taman Seri Wangi, Lorong 11, Sungai Wangi, Perak .

Date

: 12/9/2014

## **SIBIAM Home Visit by Dr. Yasmin's Team**



Home Visit Place Date : Puan Faryza's House

- : Taman Terus Maju, Sitiawan, Perak
- :27/2/2015

## Sibiam Home Visit 2016

Home Visit : Damiah's House

Place : Bar Date : 09

: Bandar Baru Selayang

:09/01/2016

Sibiam Donated 12 months supply of Dypers and Urinary Cathether's for Damiah's use

### Kenneth D Cruz

Sibiam agreed to support half the cost for a Bilateral Knee Ankle Foot Orthosis

## **CNY Party Feb 2016**





### Appreciation to our Supporters

- Rotary Club of Damansara/Nanyang Foundation Main Sponsors
- 2 England Opticals for Lucky Draw
- 3 Dr Yasmin for Hampers

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- 4 Glowmark Asia for Gifts http://www.glowmark.asia/
- 5 DBKL Library for the Venue at no Charge
- 6 JTK Consult for Admin Support
- 7 Food by JUMBO Restaurant & Catering Sdn. Bhd



- 8 Jacky for the Children's Entertainment
  - Kheeran Naidu and Avinash David for the live Music
- 10 The Lion Dance Performers



# UNCONDITIONAL LOVE SIBIAM 2017 Concert

# SIBIAM PLAN

## Client support plan

Equipment and medical supply

SIBIAM database

Home Visit Program

Rehab Service

Consultation service

Progressive Plan Education Fund

Entrepreneur Incubation Project

# Fund utilisation

Activities over 2 Years	Funds (RM)
Support for needy clients for wheelchairs, splints, walking frames, catheters, diaper	150,000
Client and care giver education programs Incl - pressure ulcer prevention and care wheelchair handling sexuality and sex in young adults with disabilities social entrepreneurship training	70,000
Public Awareness programs and campaigns Incl - Show Case Concert Radio Talk Shows Media Engagement	150,000
Other Programs : Incl - Respite care program Child support programs Home visit programs Peer support programs Family days	35,000
Education & vocational training	50,000
Administrative / operational costs	45,000
Grand Total	500,000

#### SIBIAM Charity Concert 2017 – Unconditional Love

To showcase the lives of persons afflicted with Spina Bifida from birth to adulthood and the role and impact of unconditional motherly love

#### Segments:

#### 1.Birth

This shows pre-natal and post-natal images of people with spina-bifida.

#### 2. Growing Up

As their developmental years are different from normal children, what are their special requirements and need.

#### 3.Education

Learning ability, and how they are regarded by teachers and fellow students.

#### 4. Dreams/Aspirations

What dreams and aspirations do they have? Leaving the warmth/protection of the family to move into the social environment, can they still realize these dreams & aspirations?

#### 5.Reality

In the real world, how do they cope with the disparaging attitude and 'derogatory' remarks of others? How would they face up to their doubts; and how do they prove themselves.

#### 6.Human Warmth & Coldness

There is kindness to be found everywhere waiting to be found: Love from family members, care from medical personnel, and support from friends.

#### 7.Gratitude

Allowing them to express their feelings

#### 8.Hope

What hopes do they have for this world? It may be for society at large, for mankind, or for planet Earth, etc.

#### Want to contribute?



#### Persatuan Spina Bifida Malaysia (SIBIAM)

21 Lorong Datuk Sulaiman 7, Taman Tun Dr. Ismail, 60000 Kuala Lumpur, Malaysia. 012-690 3390 info@sibiam.my www.sibiam.my facebook/spinabifida malaysia \*SIBIAM is now member of the



NTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

#### **Other Corporate Sponsors** (RM1000 to RM20000)

Acre Works Sdn Bhd, Ace Star Sdn Bhd, CQ TECH Sdn Bhd, Dover Elevators (Malaysia) Sdn Bhd, Global Technology Distribution Sdn Bhd, Hwa Hin Sdn Bhd, ELC International School, Eco World (van fitted for Disability Access), Forest Interactive Sdn Bhd, Zack Lim, JTK Consult Sdn Bhd, Keck Seng Renovation Construction Works, National Ready-Mixed Concrete Association of Malaysia (NRMCA), Mapei Malaysia Sdn Bhd, Test Sdn Bhd, MC Bauchemie (Malaysia) Sdn Bhd, LafargeHolcim, SIKA KIMIA Sdn Bhd

#### Individual Donations (RM500 to RM5000)

Ashish Kale, Chua Chee Kiong, Chung Wai Chiew, Kathleen Chew, Premieet Kaur, Ranjit Kaur, Tan Siew Wah

#### Produced by **HAN Production**

**Design Communication** Service From Graphic Design and Multimedia Society, UTAR

#### **Overall Coordination**, Patient Connection &

**Project Delivery** Dr. Yang Mee Eng, Prof. Dr. Amara Naicker Naysaduray & Ir. Dr. Kribanandan Gurusamy Naidu

MAIN MBI INTERNATIONAL SDN BHD



YAYASAN KELAB KELAB ROTARY MALAYSIA (YKKRM) **ROTARY CLUB OF DAMANSARA** 

## Unconditional Love

**CHARITY CONCERT 2017** IT'S A MOVIE, WITH LIVE PERFORMANCE OF MUSIC AND SONGS AS ITS SOUNDTRACK



#### ARTIST: YANG WEI HAN KUMAR KARTHIGESU LIAU SIAU SUAN YANG MEE ENG LIVE BAND:WVC MALAYSIA JAZZ ENSEMBLE ADIBAH NOOR (SPECIAL GUEST ARTISTE - 28TH MAY)

YANG WEI HAN **CONCERT/MUSIC/FILM DIRECTOR** TAY CHER SIANG MUSIC DIRECTO TAN CHOO HARN FILM DIRECTOR **CHAN LEE SOUND & LIGHT LIGHTING & SOUND SYSTEM** 

THROUGH THIS THEMATIC CONCERT, WE WILL EXPERIENCE THE LIFE JOURNEYS OF THE SPINA-BIFIDA COMMUNITY, TO BETTER APPERCIATE THEIR LIVES FROM BIRTH, THROUGH THEIR DEVELOPMENT AND THEIR CHALLENGES

# **Artists / Performers**



# Yang Wei Han



## Kumar Karthigesu

## Tan Siau Suan

## WVC (Jazz Band)

Yang Mee Eng

## **Performance Venue**

## Main Theatre, Damansara Performing Arts Centre (DPAC)







# Sponsorship Plan – Unconditional Love 2017

Please participate with us to serve the SB community. We are looking forward to your sponsorship as follows.

TYPE OF SPONSORSHIP: Diamond Sponsor – minimum RM75,000 Gold Sponsor – minimum RM45,000 Friends of SIBIAM – minimum RM15,000 Heartfelt Donations of any amount will be welcome *Performance tickets – RM150/ticket (minimum donation)* 

SIBIAM is partnering with the Rotary Club of Damansara and through this, the Yayasan Kelab-Kelab Rotary Malaysia (YKKRM) will issue Tax Exempt Receipts for all the funds received.

We thank you and appreciate your support!

# **Press Coverage Unconditional Love 2017**

STARMETRO, TUESDAY 9 MAY 2017

Events 9

# Raising awareness of spina bifida

Concert to also raise funds for those living with condition

By SARAH HAZIMI metro@thestar.com.mv

TRO, TUESDAY 9 MAY 2012

SPINA Bifida Association of Malaysia (SIBLAM) will be holding a charity concert at the Damansara Performing Arts Centre (DPAC) from May 26 to 28 in conjunction with its 10th anniversary.

The concert is a thematic musical that enables the audience to understand the life experience of a spina bifida sufferers.

Themed "Unconditional Love", the concert will illustrate the tough life faced by spina bifida sufferers and their families.

The concert is directed by Yang Wei Han while the music and film directors are Tay Cher Siang and Tan Choo Harn respectively. The concert will feature live music from WVC Malaysian Jazz Ensemble.

Funds raised will be used to ease the lives of people with spina bifida and their family members by providing services and facilities they need in their daily lives.

"They were born with this condition and they should be given an equal chance to live their lives like able-bodied people," said SIBIAM president Yang Mee Eng, who also has spina bifida and just received a PhD in Communications from Universiti Kebangsaan Malaysia.

The concert also aims to raise awareness about the life experience of people with spina bifida from birth.

"It will be divided into segments that will take the audience through the life of a person with spina bifida and will educate the audience about the challenges they face daily," he added.

The concert is supported by Rotary Club of Damansara and Malaysian Rotary Foundation and sponsored by MBI International.

Online ticket purchases are available at www.dpac.com.my at RM150. For details, call 012-690 3390 (Leo Yap) or 03-7710 3799 (Norliza).



(From right) Rotary Club of Damansara president Anna Rai, Mee Eng. Wei Han, artiste Liau Siau Suan, SIBIAM secretary Dr Kribanandan GN and SIBIAM committee member Kenneth D Cruz holding up the concert poster.

PATEK PHILIPPE

GENEVE

Begin your own traditio

# Donations Received June 2017 Unconditional Love Concert

TOTAL SPONSORSHIP RM 263,163 IN CASH RM 236, 914 Corporate & Individual Donations, RM 17,649 Donations at the concert & RM 8,600 Additional Ticket Sales and a FITTED VAN

TARGET RM 250,000 x 2 RM 500,000 for expenditure over 2 years

/lain Sponsor RM 100,000)	Other Corporate Sponsors (RM 1,000 to RM 20,000)	Individual Donations (RM 50 to RM 7,000	Total Donations in Cash	Grand Total
/BI International	Acre Works	Glowmark		
	CQ-Tec	Ashish Kale		
	Dover Elevators	Personal donation		
	Eco World – providing a Van fitted for the disabled	Personal Donation		
	ELC International	Personal Donation		
	Forest Interactive	Personal Donation		
	Global Technology Distribution	Personal Donation		
	Hwa Hin	Personal donation		
	JTK Consult	Personal Donation		
	Keck Seng Renovation & Construction Works	Ace star		
	Lafarge Holcim	The Gill Sisters		
	Mapei Malaysia	Personal Donation		
	Mc Bauchemie			
	Music Force Productions	Reed		
	NRMCA	The Late Mr. Gan Kit Wah		
	Propharm Malaysia Sdn Bhd	Mrs. Gan & Aunty		
	Sika Kimia	Paregroup Sdn Bhd		
	Rotary Club of Damansara	Koperasi NKFCS		
	Test Sdn Bhd			
	Zack Lim			
	Phasors Tech Sdn Bhd			
	Jean Gan Academy of Ballet & Music			
			Donations During the Concert	
			Additional Ticket Sales	
RM 100,000	RM 111,444	RM 25,470	RM 26,249	RM 263,163

# Theme Song – Unconditional Love 2017

Window for a Seed	种子的窗口	Jendela
Music: Yang WeiHan Lyrics:	杨伟汉词由	Lagu: Yang Wei Han
Liau Siau Suan	你知道吗?	Lirik: Asiah Sarji, Fuziah Kartii
As we know,	这世间上,	dan Yang Mee Eng
In this world	有人与你不同	Oh Jendela
No one is the same, we're	却又息息相通	Di dunia
told	身边某个角落	Ada yang berbeda
But really we're not dierent	被遗忘被冷落	Tapi kita sama
Yet often we're forgotten	像一颗豆	Disatu sisi tersisih
We're left out in the cold	在艰难之中成长	Dan dilupakan
Just like a Seed	凤雨中求阳光	Bagai benih
Battling all the odds to grow	炎热中不躲藏	Bercambahindah mekar
Braving storms to reach the	总有一天会茁壮	Sinar cahaya segar
sun	当生命打开额外另一扇窗	Jejak langkah baru
Away from strife we do not	0	Dituju bersama
run	整个世界多一道绚丽的彩	Bersama kita, kita ke hadapar
Intent on reaping as we	虹	Dunia yang bersinarkan
sow	从此不再蒸单害怕	harapan baru
The day, when life unlocks for	走出窗外	Kau takkan sepi lagi
us	世界依然是给勇敢的人喝	Tabahkan dirimu (Jangan
A special Window	ŧ	putus asa)
And it IIs our World with	不期望能放了解	Dunia meraikan ketabahan m
all the colours of a rainbow	只希望我能看见	Ku tetap mendoakan
So we won't feel alone,	当生命活出自己	Rasa kasih darimu
afraid	世界为我喝彩	Kau dan ku terus tabah, tabah
Beyond that rainbow		dan berani
The World awards the brave		
with		
praise and bow		
21.2		

# **Appreciation to our Existing Sponsors**

1. Hong Bee S/ B

Represented by Ms. Felicia Yap , Mr. David Poo , Ms. Rachel Heu

- 2. Hans Production Represented by Yang Wei Han
- 3. Rotary Club of Damansara Mr Francis Arulanandam , Ir. Dr. Kribanandan G N, Ms Susan Joseph Mr Jyandralal Kotari , Mr Alex Abraham, Mr Steven Gan, Jyan Kotari
- 4. National Ready Mix Association of Malaysia (NRMCA) Association CSR, Represented by Mr Eric Wong
- 5. **JTK Consult Sdn Bhd** Company CSR and Administrative Support, Ir Dr Kriban G N, Norliza and Staff

# **Appreciation to our existing Sponsors**

- 6. SIBIAM 's Website Developer Mr. Edward Boey
- 7. Media Concept Production Audio Visual Support, *Mr Randolf Wee*

### 8. Catwoman Productions

Specifically for equipment such as wheelchairs, catheters, cushions Represented by Ms. Ida Nerina - Director. producer. columnist. actor, Susan Lankaster - Producer, Director, ID & Renovation Contractor

- 9. McMohan Golf Club
- 10. Business Network International (BNI)
- 11. Creative Dreams Sdn Bhd

# Want to Contribute?

All donations of time and/or money help us achieve our goals. Please contact us at:

Spina Bifida Association of Malaysia c/o No 21 Lorong Datuk Sulaiman 7 Taman Tun Dr Ismail 60000 Kuala Lumpur, Malaysia

Mobile: 012-690 3390 Website: <u>www.sibiam.org</u> or <u>www.sibiam.my</u> Email: info@sibiam.my Facebook: www.facebook.com/spinabifidamalaysia

SIBIAM <u>CIMB</u> Bank Account: <u>80-0331313-5.</u> Please SMS or email your bank in slip to the above mobile no or email address or by cheque to <u>Persatuan Spina Bifida Malaysia</u>.

# **Sibiam Affiliations 2017**



INTERNATIONAL FEDERATION for SPINA BIFIDA and HYDROCEPHALUS

> 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 *Visit IF's Website: www.lfglobal.org*

# **Thank You**







Contact: Stephanie at 012-690 3390 or Liza at 03-7710 3799 Website: www.sibiam.my Facebook: facebook.com/spinabifidamalaysia