

3<sup>rd</sup> Floor, Bangunan Sultan Salahuddin Abdul Aziz Shah 16, Jalan Utara, 46200 Petaling Jaya, Selangor Tel: 03-79577672 Fax: 03-79570407 E-mail: pslem@streamyx.com/pslemhq@gmail.com

# Profile of Persatuan SLE Malaysia

#### What is SLE?

Systemic Lupus Erythematosus (SLE), or Lupus for short is a life-long, life-threatening autoimmune disorder that occurs when the body's immune system turns against its own tissues for reasons that are still unknown. It can cause severe damage to the body's tissues and organs i.e. the joints, skin, kidneys, heart, lungs, blood vessels, brain, etc. 90% of SLE patients are women of child-bearing age.

## **Background**

Persatuan SLE Malaysia (PSLEM) is registered with the Registrar of Societies as a non-profit, charitable organisation set up to provide social and psychological support for people suffering from Systemic Lupus Erythematosus (SLE). Starting with a small group of 10 doctors and patients in 1994, PSLEM today has more than 2,600 members all over Malaysia, comprising SLE patients, their families and healthcare professionals.

From squatting in a doctor's office in Hospital Universiti Kebangsaan Malaysia, PSLEM today operates from its Secretariat and Information & Counselling Centre in Petaling Jaya, Selangor near to the Universiti Malaya Medical Centre. A Sandakan Chapter was launched in 2004, a Penang Chapter in 2008 with its own counseling centre near Hospital Pulau Pinang, a Kuching Chapter in 2009 and a Johor Chapter in January 2010.

PSLEM's work is mainly funded by corporate donors and individual well-wishers. PSLEM is recognised by the government as a charity body and donations to the association are tax exempted.

#### **Executive Committee 2012/2014**

PSLEM's Executive Committee (Exco) consists of SLE patients, their family members and friends, and medical professionals who volunteer their time and expertise. Exco Members are elected every two years to plan and carry out PSLEM's public awareness, patient welfare, and fund-raising programmes.

### **Office Bearers**

President Vice-President

Dr. Cheah Tien Eang Ms. Chee Siew Lian Ms. Shatiffah Mohd Shah

Ms. Cecilia Wong Ting Ting

Honorary Secretary Honorary Treasurer

Ms. Radha Menon

# **Medical Advisors**

Prof. Datin Dr. Norella Kong Dr. Morris Wo Chee Yuen Dr. Heselynn Hussein

# **Counselling Advisors**

Prof. Dr. M. Parameshvara Deva Dr. Jenny M.P. Deva

Dr. Jenny M.P. Deva Ms. Valerie Jaques

# Executive Secretary :

Committee Members
Assoc Prof Dr. Cheng Fan Fah
Assoc Prof Dr. Esha Das Gupta
Ms. Siti Sarah Bt Abdul Razak

Nursing Sister Ong Bee Lee Ms. Liew Nyet Nyuen Ms. Helen Yong Wai Yuen

#### **Sub-Committee Members**

Assoc Prof Dr Ng Chin Teck Dr. Fariz Yahya Dr. Yeap Swan Sim Ms. Loh Pui Yee Ms. Lucy Goh Kim Hong Dr. Fauziah Bt Raji

# Ms. Winnie Low Wai Kuen Ms. Cheah Geik Kim Ms. May Yap Mui Lee Ms. Chong Chia Chee Ms. Harman Mohan Kaur Ms. Lim Wan Chin

#### State Representatives

Johor – Dr. Pagalavan Letchumanan Melaka – Ms. Jennifer Yu Swee Mee Perak - Ms. Magdelene Leong Yeow Yit Pulau Pinang - Dr. Tan Bee Eng

Sabah - Ms. Monita Cheong Wan Yee & Ms. Jean Chan Chok Fun

Sarawak – Dr. Teh Cheng Lay Terengganu - Ms. Siti Nurbaya Zakaria Members of PSLEM's Executive Committee are allocated duties under six Sub-Committees:

- 1) Corporate Care Sub-Committee
- 4) Volunteers Sub-Committee,5) Patients Support Sub-Committee, and
- 2) Social Events Sub-Committee3) Education Sub-Committee
- 6) Editorial Sub-Committee.

#### **Our Activities**

We work in partnership with the corporate sector and the public to raise funds for our various activities:

- The Lupus Information & Counselling Centre in Petaling Jaya, which also operates a 12-hour SLE helpline for SLE patients and members of the public all over Malaysia.
- ii) PSLEM's SLE patient support groups in Pulau Pinang, Johor Bahru, Kuching and Sandakan. PSLEM targets to have at least one patient support group in each state within the next 10 years.
- iii) Training patients who are coping well as SLE para-counsellors to be on duty to provide free counselling services at major hospitals where SLE patients receive treatment.
- iv) Patient education programmes to provide patients and their family members with better coping skills: group therapy sessions, talks, public forums, and family camps.
- v) Public awareness programmes. With greater public awareness, SLE sufferers will be more likely to get an earlier diagnosis, thereby improving their chances of survival.
- vi) Financial assistance for needy patients who have to undergo joint replacement and cataract operations due to the side effects of their corticosteroid treatment. The SLE Fund subsidises up to 90% of the cost of the patient's prosthesis or lens implant.

#### **Future Plans**

As the only organisation in Malaysia set up to help people suffering from SLE, PSLEM has to work towards extending its reach to every State to benefit all SLE sufferers in the country. Besides its Secretariat in Petaling Jaya, PSLEM is targeting the setting up of five Regional Counselling Centres as follows:

- · In Georgetown, Penang to cover the northern region
- In Johor Bahru, Johor to cover the southern region
- In Kuantan, Pahang to cover the East Coast States of Peninsular Malaysia
- In Kota Kinabalu to cover the State of Sabah
- In Kuching to cover the State of Sarawak

# How you can support us

- Donate we issue tax exemption receipts. You may donate to Persatuan SLE Malaysia via CIMB Cares under CIMB Clicks (www.cimbclicks.com.my).
- Sign-up as a volunteer so we could have a pool of volunteers whom we could call upon to assist in our various activities. Call us at tel. 03-7957 7672 or email us at <u>pslem@streamyx.com / pslemhq@gmail.com</u>

## **Contact Details:**

Address

: 3rd Floor, Bangunan Sultan Salahuddin Abdul Aziz Shah,

16, Jalan Utara, 46200 Petaling Jaya, Selangor

Tel No. : 03-7957 7672 Fax No. : 03-7957 0407

E-mail Address : pslem@streamyx.com / pslemhg@gmail.com

Website : www.lupusmalaysia.org

Facebook : <a href="http://www.facebook.com/persatuansle.malaysia">http://www.facebook.com/persatuansle.malaysia</a>

Executive Secretary : Ms Cecilia Wong

**HELPLINE No. 603-7957 7672** (From 9am to 9pm daily)

19-12-2012 Page 2 of 2