



# GONG XI FA CAI!

WISHING YOU A BLESSED NEW YEAR FILLED WITH GOOD FORTUNE AND LAUGHTER!

MALAYSIA  
**LYSOSMAL**  
DISEASES  
ASSOCIATION





# Message From The President

2019 had been a rather stimulating yet inspiring year. We have been working hard since the establishment of MLDA to raise fund and spread the needed awareness for the betterment of lysosomal storage disease(LSD) patients in Malaysia but we strive even harder for the same cause ever since we lost the tax exemption status back in 2016.

Mere words could not describe how blessed and thankful we are to have your continuous support throughout the journey. In summary, we managed to save 54 LSD lives with the total estimated cost of RM53 million per annum. Of course, Government provided 60% of the total funding while the balance was unanimously contributed by corporates, Zakat, pharmaceutical companies and MLDA.

Yet we were hit with another storm when it was announced that there was a budget cut of RM6 million for Rare Disease patients in Budget 2020. MLDA immediately bought RM300,000 worth of medicated enzymes to replenish the stocks in Hospital Kuala Lumpur so that their treatment can continue as usual.

YB Dr Lee Boon Chye, our Deputy Health Minister made a strong verbal assurance to continue medication for existing patients when we had a meeting with him recently. The only concern now is the remaining 9 patients in the waiting list as resources are limited.

In 2020, we will be working alongside with the Ministry Of Health to come up with a Rare Disease Fund to create a sustainable funding mechanism in Malaysia. We will also resubmit our application for tax exemption status.

Apart from that, there are numerous exciting activities planned for year 2020 such as #gogohopeand year end charity dinner-we look forward to your continuous support!

Finally we wish you a Happy New Year and Gong Xi FattChai!



Yours truly ,  
IrLee Yee Seng  
President of MLDA.

# 2011-2019 MILESTONE



Every Life Counts Campaign at Bangsar Village launch by Pengarah Perkembangan Perubatan.

**2012**



Remarkable Charity Dinner with Yang Di-Pertuan Besar Negeri Sembilan and Health Minister which saved 7 patients with RM2 Mil allocation. 100 people doing Ice Bucket Challenge to raise funds.

**2014**

**2011**

Soft launch of MLDA 10 Oct by Taiwan Ambassador 罗贯中大使



**2015**

Since 2015 Puchong Ryder Club has rendered funding assistance to MLDA annually.



**2013**

The first corporate sponsor from IJM Land via S2 Run and continuing helping MLDA until now.





# 2011-2019 MILESTONE



MLDA and BAC successfully organized charity dinner at Empire Mall and convince MOH to continued funds for 6 patients.

**2016**

LSD PATIENTS RECEIVED ERT TREATMENT FROM 2017-2018



Malaysia Government provided RM 10 million budget for LSD children and saved 13 patients in the waiting list.

**2018**

**2017**

Hunt For Hunter Programme (Genetic Screening) supported by Government funding successfully detected 28 carriers.



**2019**

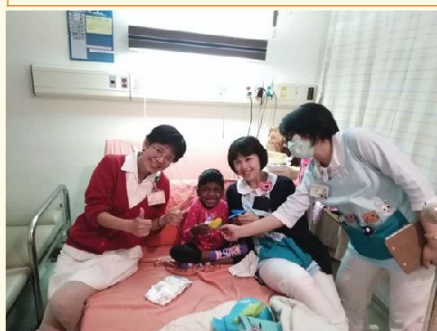
Organized Run For Rare 2019 partnering with Sunway Group and EC Pixels and officiated by Health Minister with 3,300 runners.



# WELFARE

## MEDICAL ASSISTANCE

May 2019	MLDA procured winge surecan needles value at <b>RM1,237</b> for patients undergo ERT treatment at Hospital Kuala Lumpur (HKL).
Aug 2019	MLDA agreed to help Mathana who undergo neck surgery at Taiwan value at <b>RM80,000</b> .
Sept 2019	Loaned a CPAP to Bung Yu Heng value at <b>RM5,450</b> .
Dec 2019	Loaned a Bipap to Muhammad Adib Bin Mohd Hafis after battery replacement of <b>RM3,900</b>
Dec 2019	Spent <b>RM292,636.60</b> on ERT enzyme for patients
2019	Spent <b>RM14,781</b> to perform blood test for new patients.



## EDUCATION ASSISTANCE

Aug 2019	Reimbursed College Fee for Khairul Nazmi, MPS Type II with a total value of <b>RM7,508</b> .
----------	--

## WELFARE

2019	MLDA received <b>RM50,000</b> donation from Mah Sing Foundation, MLDA use this donation to support <i>"Bantuan Sara Hidup"</i> for all 16 families and also yearly subsidy to all patients.
2019	MLDA received <b>RM10,000</b> grant from Ministry of Health (MOH), MLDA decided to use all for DNA test.
2019	Spent <b>RM84,758.95</b> for the yearly subsidy of <b>RM1,500</b> max to each patient. And, gives out special subsidy to needy families when needed
On-going	<b>RM 150</b> of <i>"Bantuan Sara Hidup"</i> has been given every month to 21 patients of 16 families.



# 2019 GALLERY



1 11/1 AUDAX Cycling BRM300

2 31/1 Hope 2.0 Book

3 3/3 World Rare Disease Day: Run For Rare

4 9/3 Art Exhibition: Rare Lives

5 20/4 AGM Meeting & Gathering

6 1/5 HKL City Run

7 18/5 BAC Charity Bazaar



# 2019 GALLERY



8



9



12



11



13



14



10

- |    |         |                           |    |       |                                    |
|----|---------|---------------------------|----|-------|------------------------------------|
| 8  | 26/5    | Ride with Hope Campaign   | 12 | 20/9  | Puchong Ryder Club Charity Dinner  |
| 9  | 4/8     | IJM Land Marathon Run     | 13 | 11/10 | Mah Sing Foundation Charity Dinner |
| 10 | 18-22/8 | Psrid-Brest-Paris: 1200KM | 14 | 1/11  | Pompe Conference, Singapore        |
| 11 | 7/9     | Mary Sia Charity Concert  |    |       |                                    |





## PERTUBUHAN PENYAKIT LISOSOMAL MALAYSIA

MALAYSIA LYSOSOMAL DISEASES ASSOCIATION

马来西亚溶酶体疾病协会 (Reg. No.:2621-11-NSE)

No. 30-11, Geo Sense, Jln Lagoon Selatan, Bdr. Sunway, 47500 SJ, Selangor.

Contact 电话: 010-351 5525

Email 电邮: [donation.mlda@gmail.com](mailto:donation.mlda@gmail.com)

Website 网址: [www.mymlda.com](http://www.mymlda.com)

### Contribution 捐助 (Please tick/fill in appropriately 请在正确的格子内打勾及填妥资料)

- ☐ **Monthly** 每个月    ☐ **RM30**    ☐ **RM50**    ☐ **RM100**    ☐ **Other其他: RM** \_\_\_\_\_  
☐ **ONE-TIME** 一次性    ☐ **RM100**    ☐ **RM200**    ☐ **RM300**    ☐ **Other其他: RM** \_\_\_\_\_

### Payment Mode 付款方式(Please tick/fill in appropriately 请在正确的格子内打勾及填妥资料)

- ☐ **Cheque** 支票    Number 号码: \_\_\_\_\_    Paying Bank 支付银行: \_\_\_\_\_  
 (Payable to 支票抬头 **PERTUBUHAN PENYAKIT LISOSOMAL MALAYSIA**)  
☐ **Cash** 现金 (For direct deposit into 现款汇入 **Public Bank A/C No.: 3169692035**)  
 (Please send/email the deposit slip together with this form, 请通过邮寄/电邮附同捐款表格寄回存款表格单据)  
☐ **Online Transfer** 网上转帐    Ref. No. 转帐号码: \_\_\_\_\_

### Tell us a little about yourself 捐助人资料

(\* Please delete whichever not applicable & fill up appropriately \* 请选择性删除及填妥资料)

Name 个人名字/( Company公司名号)\*: .....

IC No. 登记号码/( Company Reg. No.公司注册号码) \*: .....

Address地址: .....

.....

.....

Tel电话: ..... H/P手机: ..... Email电邮: .....

Date日期: \_\_\_\_\_

Signature签名: \_\_\_\_\_

I hereby acknowledge this form has been filled out by myself and allows deductions to be made by MLDA as above details given.  
我在此证实我个人亲自填写表格, 并允许马来西亚溶酶体疾病协会依照表格做出适当扣除。

**Malaysia Lysosomal Diseases Association (MLDA) was granted "tax exemption" status since 2012.**

马来西亚溶酶体疾病协会在2012年已取得扣税资格, 您的捐款将可扣税。

### For Office Use

Date Received: \_\_\_\_\_

Handled by: \_\_\_\_\_