

# HAPPY CHINESE NEW YEAR!



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

A greeting from Malaysia Lysosomal Diseases Association

# Message From The President

2020 turned out to be an unexpected year with the global hit of Covid-19 outbreak. Most of our fundraising activities had to be postponed or cancelled due to the lockdown implemented. The silver lining is that despite the drop in donation, we managed to provide monetary assistance to 72 families worth **RM91,606** and our very own MLDA Subsidy to 16 poor families worth **RM 37,800**.

We were fortunate to be able to physically attend 2 major events before the lockdown was implemented:

- 29 Feb 2020- 4 Mar 2020: In conjunction with World Rare Disease Day 2020 (WRDD), MLDA participated in MY1200, an Ultra-Distance cycling organised by International Islamic University Malaysia (IIUM) Kuantan where Prof Dr Jamal contributed to 2 MLDA patient family in Kuantan.
- 8 Mar 2020: MLDA's 10<sup>th</sup> Annual General Meeting (AGM) at Hotel Unicorn, Kuala Lumpur

December 2020 was really a spectacular month (despite the Covid-19 pandemic) for us at MLDA where we met many Samaritans namely:

- Oji Asia Household Products Sdn Bhd sponsored Diapers to 55 MLDA patient families in need.
- MLDA was invited to participate in Asia-Pacific Economic Cooperation (APEC) Virtual Policy Dialogue on Rare Diseases in Malaysia & the Asia-Pacific where our Ministry of Health (MOH) announced a Malaysian Orphan Medicine Guideline, this remarkable achievement is another step closer to having an Orphan Drug Act in Malaysia, which is what all Rare Disease NGOs like MLDA is hoping for!
- We are glad to announce that after much trials and tribulations, MLDA is now a tax excepted NGO. We hope that by gaining this status, more donations will be pouring in!
- Launch of Rainbow Alpha Grain (RAG), a type of Nutritional Drink as part of the long term sustainable charity sales program which was initiated by both Mr Wong Pau San, MLDA Advisor and Dato John from the Puchong Ryder Club.

Despite the alarming rate of Covid-19 cases, we are determine to bring HOPE to all in 2021. Hence on 15 Jan 2021, we launched Gogohope Virtual Sport Challenge, which allow the participant to choose to either Run or Ride. The objective is to motivate and encourage everyone to participate in the Beauty of Malaysia Photography contest to promote the message that despite facing such a trying year caused by Covid-19 pandemic, we too can capture and share beautiful images. Let us create another chapter of memorable picturesque together!

Chinese New Year 2021 will be very different this year that we might unable going back to our hometown but we have to be thankful. As long as we are healthy, our loved ones are safe and beside us and we have a roof over our head and sufficient food on our table we are considered blessed!

Here is wishing you and your family a Happy New Year and Gong Xi Fatt Chai 2021!

Yours truly,



Ir Lee Yee Seng

President of MLDA.





# 2020 ACTIVITIES



**29 Feb 2020-4 Mar 2020**

Ride with Hope team from MLDA completed the 1200km ride in conjunction with WRDD. Event organised by IIUM Kuantan.



**July 2020**

Visited YB Senator Ras Adiba

**April 2020**

Visited Deputy Health Minister YB Dato Dr Haji Nor Azmi.

**8-9 March 2020**

Counseling Boot Camp and AGM 2020 at Hotel Unicorn KL

**13 Dec 2020**

Launch of the sales of Rainbow Alpha Grain via FB LIVE



# ASSISTANCE PROVIDED IN YEAR 2020

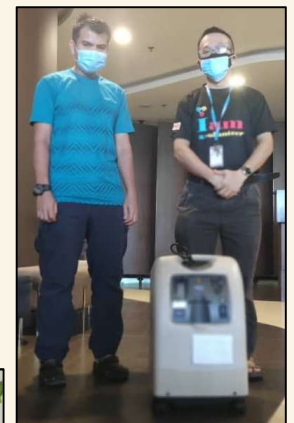
## MEDICAL ASSISTANCE

May 2020	Loan a wheelchair to Ardi at the cost of <b>RM3,700.</b>
Sept 2020	Loan Oxygen concentrator tank to Muhammad Adib Bin Mohd Hafis value at <b>RM3,800.</b>
Dec 2020	Loan a CPAP to Amirul Bin Bhasaruddin value at <b>RM3,700.</b>
2020	Spent <b>RM6,500</b> on prenatal pregnancy incentive.
2020	Bought <b>RM137,978</b> worth of ERT enzyme for patients to undergo ERT treatment.
July 2020	Loan a CPAP to Muhd Hazim worth <b>RM 4,000.</b>



## WELFARE

2020	MLDA spent <b>RM7,000</b> to purchase facemasks to give away to our patients and donate 40 boxes to Hospital Kuala Lumpur during MCO. Also bought a refrigerator and donated to Genetic Clinic HKL to support members' frozen food business.
2020	Spent <b>RM91,606</b> for the yearly subsidy of RM1,500 max to each patient.
On-going	<b>Spent RM37,800 in 2020 as RM 150</b> of " <i>Bantuan Sara Hidup</i> " has been given every month to 21 patients of 16 families.



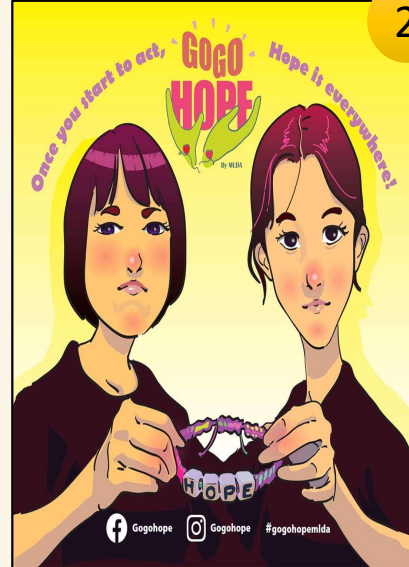


# Upcoming 2021 Project

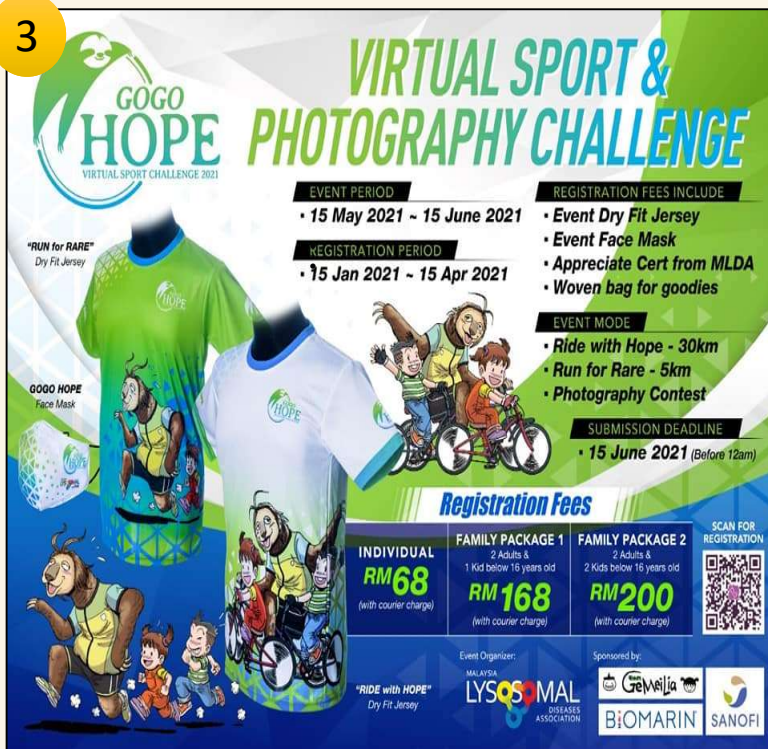
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2



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1

Rainbow Alpha Grain sustainable income program is an ongoing project. Click on the link below to purchase <https://www.rainbow191314.com/?ref=MLDA>

2

Gogohope Virtual Sport Challenge Registration Website <https://www.ticket2u.com.my/event/23962/gogohope-virtual-sport-challenge>

3

Gogohope bracelet ongoing project. RM25/piece.

4

Persatuan Bahasa Cina Universiti Malaya will carry out a series of activities including contests to raise awareness on Lysosomal Storage Diseases. More information is available on our [Facebook \(MLDA\)](#)

5

MLDA's 10<sup>th</sup> Annual Anniversary (Subjected to pandemic condition)

6



## PERTUBUHAN PENYAKIT LISOSOMAL MALAYSIA MALAYSIA LYSOSOMAL DISEASES ASSOCIATION

**马来西亚溶酶体疾病协会** (Reg No: PPM 018-05-25052011 old:2621-11 NSE)

30-11, Geo Sense, Jln Lagoon Selatan, Bdr Sunway, 47500 Subang Jaya, Selangor.

Website: [www.mymlda.com](http://www.mymlda.com) Email: [donation.mlda@gmail.com](mailto:donation.mlda@gmail.com)

FB: Malaysia Lysosomal Diseases Association Contact no: 019-6899620

**Public Bank A/C No. 3169692035 (PERTUBUHAN PENYAKIT LISOSOMAL MALAYSIA)**

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

**Monthly 每个月**

☐ RM 30 ☐ RM 50 ☐ RM 100 ☐ Other Amount 其他: RM \_\_\_\_\_

**One-Time 一次性**

☐ RM 100 ☐ RM 200 ☐ RM 300 ☐ RM 500 ☐ Other Amount 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 No. 号码: \_\_\_\_\_

☐ Cash Deposit 现金存款 Date/日期: \_\_\_\_\_ Ref. No. 存款号码: \_\_\_\_\_

☐ Online 网上转账 Date/日期: \_\_\_\_\_

**If transfer thru 3<sup>rd</sup> party 如通过别人户口转账 3<sup>rd</sup> Party Name 转账者名字: \_\_\_\_\_**

**Malaysia Lysosomal Diseases Association (MLDA) was granted "tax exemption status" on 2021.**

**马来西亚溶酶体疾病协会已在 2021 年取得扣税资格。**

We need your personal/company particulars for us to issue you a tax exempted official receipt.

Pls email or Whatapps this donation form back to us. Thanks A Million!

我们需要您的个人/公司资料来发免税收据，请将这乐捐表格电邮或 Whatapps 给我们，感恩！

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

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: \_\_\_\_\_ Email 电邮: \_\_\_\_\_

