MIKU CHALLENGE

RIDE WITH HOPE | 12 JUNE 2022

https://cps4.me/miku-challenge

MIKU CHALLENGE
WORLD RARE DISEASE DAY 2022

MALAYSIA LYSOSOMAL DISEASES ASSOCIATION

PERSATUAN PENYAKIT JARANG JUMPA MALAYSIA
(Malaysian Rare Disorders Society)

PRADER - WILLI SYNDROME MALAYSIA

P.B.N.S

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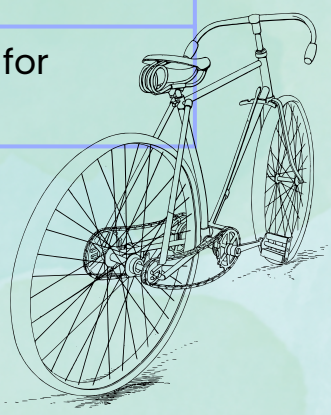
Agenda Nasional Malaysia Sihat

RIDE WITH HOPE - MIKU CHALLENGE 2022

ITINERARY

7.30 am	Fellowship Ride Miku Challenge 74kM Flag Off by VIP
7.45 am	16kM Ride Flag Off by VIP
8.00 am	Fun Walk/Ride with patient family - 1kM
9.00 am	Breakfast with Invited Guest & Patient Family
9.30 am	Organizing Chairman Speech
9.35 am	YB Khairy Jamaluddin Video Speech
9.40 am	Mock Cheque & Appreciation Certificate Presentation for Klanggroup Holdings Sdn Bhd and Sanofi-Aventis (Malaysia) Sdn Bhd
9.45 am	Appreciation certificate presentation to Oji Asia Household Product Sdn Bhd and Mawar Medical Center
9.50 am	Mock Cheque Session for MOH's Rare Disease Trust Fund
10.00 am	Photography Session & Disperse
10.00 am - 12.00 pm	Rider will slowly return back to Dataran Rembau for Photography Session & Disperse



UCAPAN PERASMIAN YB KHAIRY JAMALUDDIN

Assalamualaikum Warrahmatullahi Wabarakatuh dan Salam Keluarga Malaysia Sihat Sejahtera.

Saya mengucapkan setinggi-tinggi penghargaan dan terima kasih kepada para penganjur program Miku Challenge iaitu Malaysia Lysosomal Diseases Association(MLDA) bersama Malaysian Rare Disorders Society (MRDS), Persatuan Sindrom Prader-Willi Malaysia (PWS) dan Persatuan Berbasikal Negeri Sembilan (PBNS) atas usaha ini, bersempena dengan Hari Penyakit Jarang Jumpa Sedunia.

Dengan tema tahun ini "Kongsi Warna Anda"(Share Your Colours), kami di KKM akan berusaha mempertingkatkan mutu perkhidmatan serta akses kepada terapi dan mengurangkan stigmatisasi para pesakit jarang jumpa serta keluarga mereka, yang merangkumi orang yang hidup dengan lebih daripada 7,000 penyakit rare disease. Penyakit "Rare Disease" bukanlah perkara yang selalu kita dengar, namun penyakit ini juga menjadi keutamaan kami di KKM kerana ada nyawa yang hilang akibat daripada tidak mendapat rawatan dalam masa yang tepat.

Kesedaran masyarakat adalah amat penting agar kita menjadi lebih perihatin untuk berinteraksi dan bergaul dengan para pesakit jarang jumpa dan penganjuran program "Miku Challenge" ini adalah antara platform untuk memperkenalkan atau memberi kesedaran kepada masyarakat tentang penyakit ini.

Akhir kata, syabas dan tahniah saya ucapkan kepada para penganjur yang telah berusaha keras menggembleng tenaga untuk merealisasikan program "Miku Challenge" ini. Semoga program seperti ini dapat diteruskan lagi pada masa-masa akan datang. - Sekian.

UCAPAN PENGERUSI PENGANJUR, IR LEE YEE SENG

In conjunction with World Rare Disease Day 2022 (28 Feb 2022), Malaysia Lysosomal Diseases Association (MLDA) will be organising our pioneer Ride with Hope in Rembau together with the Malaysian Rare Disorders Society (MRDS), Persatuan Sindrom Prader-Willi Malaysia (PWS) and Persatuan Berbasikal Negeri Sembilan. The aim of the event is to create the needed awareness pertaining rare diseases (RD) in Malaysia. The total proceed raised will be contributed towards supporting RD patients in Malaysia as we strive to assist the RD community and patients in improving their quality of life.

Bkt Miku, Rembau, best known as one of the steepest hills in Malaysia has been selected as the event location. It will not only test the endurance level of both new and seasoned riders but also challenge participants' resolve and resilience. By participating, we hope that with each pedal stroke, the experience will help create awareness and act as a reminder of our RD individuals and their families as they continue to fight the good fight each day for equal rights and a life with dignity and wellbeing.

Rare Disease Day is the globally-coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease.

Every year, patient groups and stakeholders from Malaysia join forces with advocates from across the globe to raise a spotlight on issues faced by rare disease individuals and their families.

This year, we are still under the threat of Covid-19 pandemic, this pandemic has cause so much despaired and frustration especially when the entire country were lock down twice. The life of some rare disease patients are similar to lock down, everyday is a MCO day due to the multiple challenges that running through their life. Miku Challenge is to give them Hope, so that we get more people to come in to give them support to continue to live with dignity.

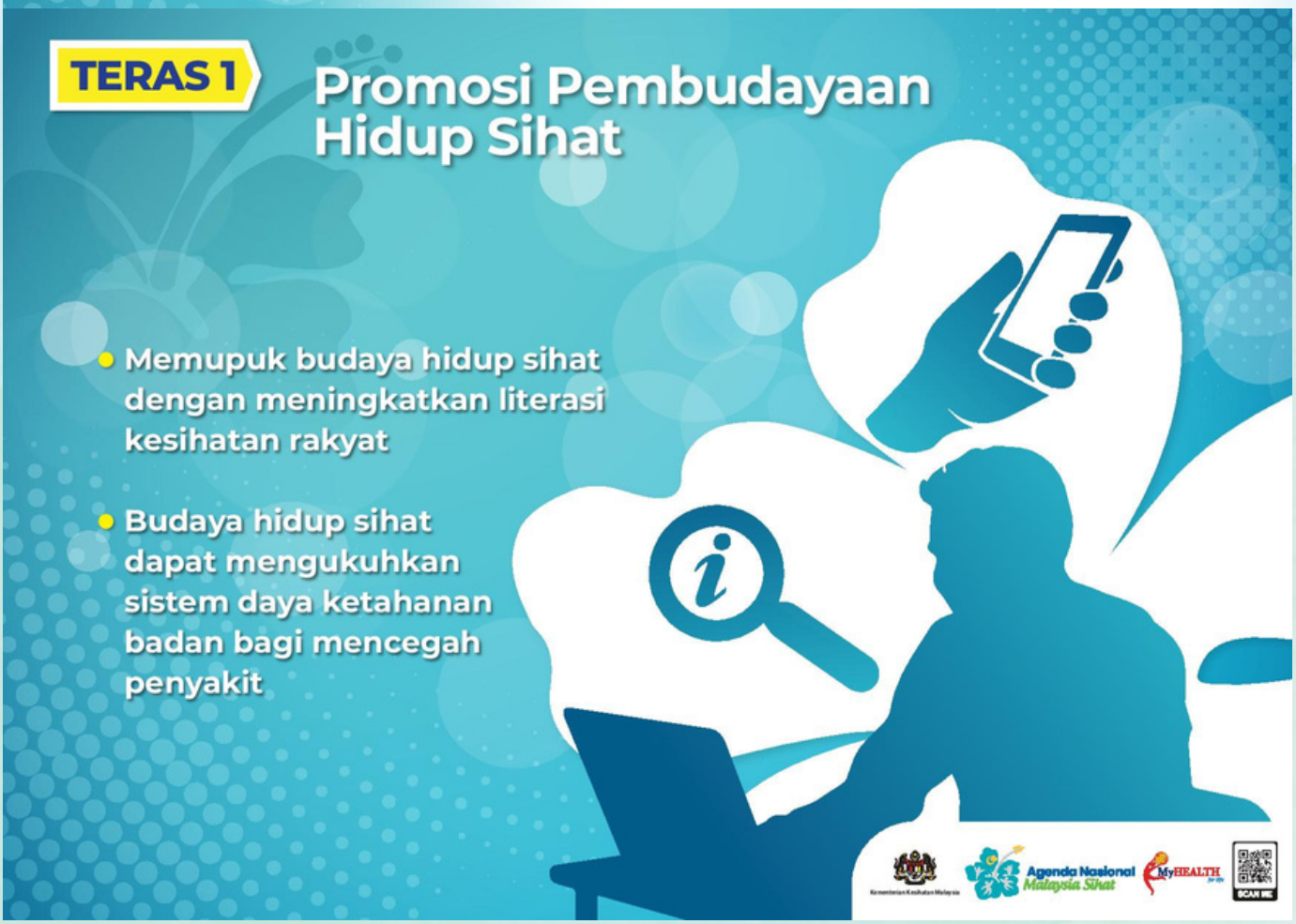
The inception of Miku Challenge is when Ministry of Health YB Khairy Jamaluddin pledge to increase budget for Rare Diseases patients in 2022. This budget will be used to reimburse the high medication cost and help rescue every single life. The path has been undulating for our journey. We are grateful YB breaking the wind resistance in the palethon, this will definitely help light up hope for many rare diseases patients in Malaysia.

Lastly, thank you to all the riders, our sponsors, volunteers, various government agencies for supporting Miku Challenge, with your help breaking the wind resistance, our journey will be better, easier and brighter!

Yours Truly,

Ir. Lee Yee Seng
PMC, P. Eng ,MIEM,MTAM,CompetentEng(11kV),AseanEng,
APEC Eng, IntEng(MY), MBA
Organizing Chairman

Bagi meningkatkan amalan hidup sihat dikalangan rakyat Malaysia, Miku Challenge telah mengambil seruan kerajaan melalui Agensi Nasional Malaysia Sihat (ANMS) yang diperkenalkan oleh YAB Dato' Sri Ismail Sabri Yaakob, Perdana Menteri Malaysia pada tahun 2020. Inisiatif ini menfokuskan kepada Teras 1 iaitu promosi pembudayaan hidup sihat dengan membantu orang ramai untuk bersukan sambil meningkatkan ketahanan diri.



ABOUT MLDA

The Malaysia Lysosomal Diseases Association ("MLDA") is a non-profit organization which advocates for patients' rights to a sustainable health care and support system. It also raises the awareness of the general public about the life threatening Lysosomal Storage Diseases(LSD). We are dedicated to improve the lives of all patients afflicted by Lysosomal Storage Diseases via;

- Advocating for the establishment of a sustainable healthcare system for all LSD patients
- Creating greater awareness of more than 50 types of Lysosomal Storage Diseases
- Supporting research for a cure and treatment that will improve the quality of life of the patients
- Developing and sustaining an effective patient community network that provides comprehensive support for the ever-increasing needs of individuals and families affected by Lysosomal Storage Diseases.

As our association continues to grow, we hope to be able to offer certain programmes and services to our members. These will be structured to provide our members with the latest information, opportunities to build a strong support network and the access to the latest medical services. Some of the services we hope to be able to offer in the near future are;

- Information & Updates on LSD
- Counselling Services
- Financial advice and support

We also hope to be able to provide programmes that will enable us to continue to spread awareness and build strong support networks among patients, families and other interested parties.

MLDA'S JOURNEYS

2011

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

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

2012

2013

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

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

2015

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

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2019

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

2022

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

2016

Malaysia Government provided RM10 million budget for LSD children and saved 13 patients in the waiting list.

2018

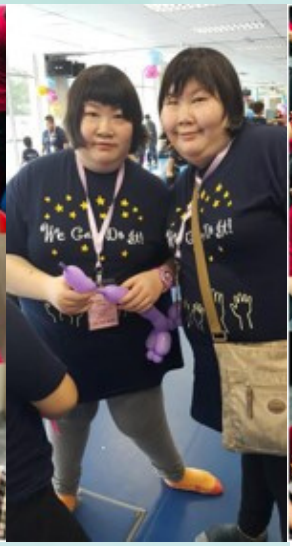
2017

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

ABOUT MALAYSIA PRADER-WILLI SYNDROME ASSOCIATION

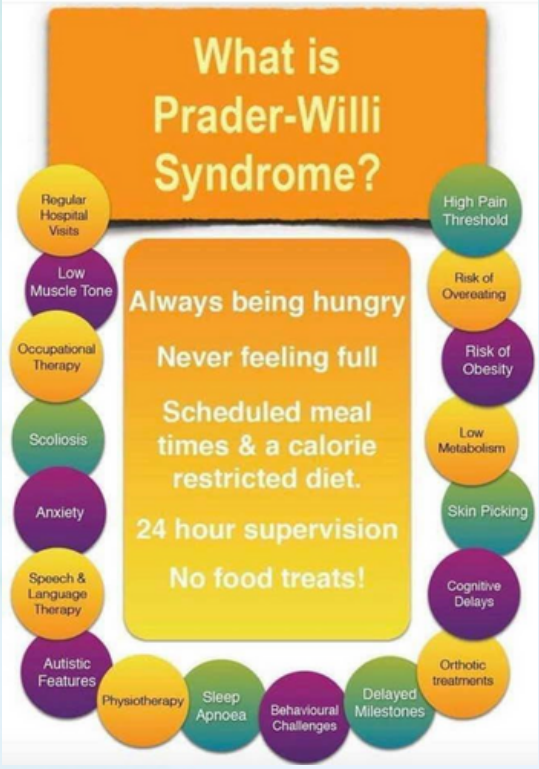
PRADER - WILLI SYNDROME MALAYSIA

Prader-Willi syndrome is a rare genetic disorder caused by abnormalities in a particular region of chromosome 15. The Malaysian Prader-Willi Association was established in 2016 by a group of concerned parents.



SYMPTOMS AND CHARACTERISTICS

- Hyperphagia (abnormally increased appetite/ never feeling full/constant craving for food).
- Obesity and associated problems like diabetes and cardiac problems.
- Other characteristics include low muscle tone, decreased cognitive ability and behavioural problems.
- Need constant supervision (24 hour round the clock supervision).




STILL HUNGRY FOR A CURE
FEATURING:
Join us via FBLive for an honest conversation on Prader-Willi Syndrome from Challenges to Hope
Persatuan Sindrom Prader-Willi Malaysia
Azhar Talib, President, PWSAM
James O'Brien, Vice President, IPWSO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December 2019


BFM 89.9
The Business Station
PRADER - WILLI SYNDROME MALAYSIA
Brain Waves radio interview
Monday 16 November 2020, 4pm
Encik Azhar Talib, President PWSM, shares about the Prader-Willi Syndrome community in Malaysia, and how


#CHAMPION FOR
RARE
BE CHAMPION FOR RARE
SUPPORT RARE
GET TO KNOW RARE
FUN ACTIVITIES FOR KIDS
DATE: FEB 28 - MAR 01, 2020
TIME: 10AM - 10PM
VENUE: MYTOWN MALL, CHERAS
EXHIBITION BOOTH: AT THE LINK

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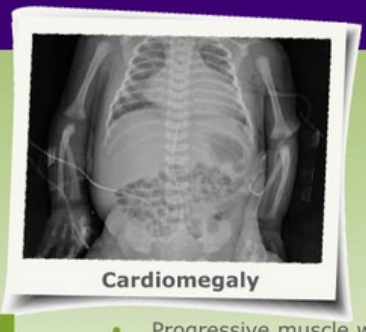
DO YOU RECOGNISE THESE RARE DISEASES?


Joint and skeletal dysplasia

Mucopolysaccharidosis (MPS)[2]

- Abnormal development of joint and bones
- Collapse of one or more vertebral bodies
- Coarse facial features
- Claw hand deformity
- Swollen liver and spleen
- Tissues protrude in abdomen
- Corneal clouding (in MPS type I)


Cardiomegaly

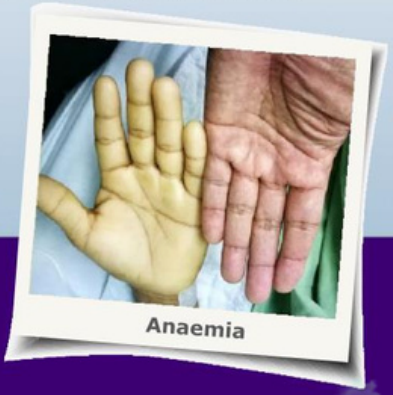
Pompe Disease[3]

- Progressive muscle weakness
- Decreased muscle tone
- Enlarged heart
- Weakness of lower limb
- Respiratory impairment
- Frequent respiratory infections
- Sleep disorder
- Drowsy

Early recognition of rare diseases can improve patient outcomes[1]

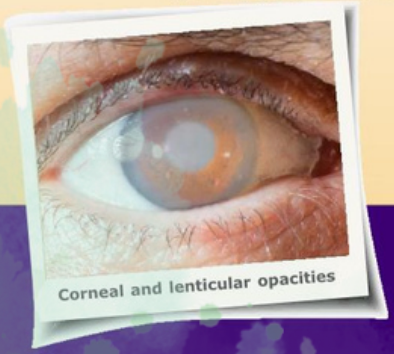
Gaucher Disease[5]

- Anaemia
- Low blood platelet count
- Chronic bone pain
- Skeletal abnormalities
- Swollen liver and spleen
- Death of bone tissue due to a lack of blood supply (eg: tiny breaks in the bone and the bone's eventual collapse)


Anaemia

Fabry Disease[4]

- Numbness or burning feeling in extremities
- Inability to tolerate heat
- Early stroke and transient ischaemic attack
- Skin lesion or wound
- Kidney failure
- Cardiovascular dysfunction
- Corneal and lenticular opacities (generally does not affect vision)


Corneal and lenticular opacities

Early diagnosis of rare diseases is the **first and key step** towards better outcomes

Early diagnosis

Allow early intervention while avoiding unnecessary health care

Better disease management

Good disease prognosis

Improve patients' quality of life

References

1. Esquivel-Sada D, Nguyen MT. Diagnosis of rare diseases under focus: impacts for Canadian patients. *J Community Genet.* 2018;9(1):37-50. **2.** Galimberti C, Madeo A, Di Rocco M, Fiumara A. Mucopolysaccharidoses: early diagnostic signs in infants and children. *Ital J Pediatr.* 2018;44(2):7-16. **3.** Barba-Romero MA, Barrot E, Bautista-Lorite J, *et al.* Clinical guidelines for late-onset Pompe disease. *Rev Neurol.* 2012;54(8):497-507. **4.** Germain DP. Fabry disease. *Orphanet J Rare Dis.* 2010;5(1):30. **5.** Linari S, Castaman G. Clinical manifestations and management of Gaucher disease. *Clin Cases Miner Bone Metab.* 2015;12(2):157-64.

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