

President's Message

Alhamdulillah, MRDS has successfully completed another year and has taken incremental steps in forwarding information and promoting public awareness. MRDS held a variety of activities to bring the message of rare disorders to the public and amongst them, holding a press conference to publicise Rare Disease Day that was observed for the first time in Malaysia and preparing educational materials like posters, a book and brochures. MRDS has applied for tax-exempt status and is also looking for suitable partnerships that will benefit members.

Rare Disease Day 2010 Exhibition

An exhibition was organized at University Malaya Medical Centre. It provided information on MRDS as well as details on Rare Disease Day and its significance.

Press Conference in conjunction with Rare Disease Day 2010

The press conference was held to create awareness among the public on the existence of rare disorders in the society and to hopefully stir the public to play a part in providing support in one way or another to patients and families. It is also hoped that the government's attention and commitment towards this cause would be increased as public awareness elevates. Speakers at the press conference included MRDS President, Dato' Hatijah Ayob and consultant paediatrician cum head of University of Malaya Medical Centre genetics unit, Prof MK Thong.

Rare Disease Day 2010 Gathering

A social gathering for people with rare diseases and their family members was held on 28th February at the home of the MRDS President. It provided an avenue for members to meet and share their stories with each other as well as for MRDS to reach out to new members and explain to them the role of the society. The evening also turned out to be fun for the children as they were kept busy with sand art and balloons.

Participation in Events

MRDS participated in a health exhibition held at Second College, University Malaya in conjunction with its 50th anniversary. MRDS also had an opportunity to set up a booth at the Medical Genetics Conference organized by the Medical Genetics Society of Malaysia.



Dato' Hatijah Ayob, MRDS President (right)



Rare Disease Day 2010 Exhibition



(Left to right)
Datuk Tunku Zahiah binti Tunku Sulong, MRDS Patron; Prof Dr Thong Meow Keong, genetics consultant; Dato' Hatijah Ayob, MRDS President and Nick Atkinson, MRDS volunteer at the press conference.



Rare Disease Day gathering



Annual General Meeting 2010

At the 4th AGM, MRDS invited Tuan Hj Mohd Khir Omar, the Deputy Director of Bahagian OKU, Jabatan Kebajikan Masyarakat to give a talk on the Persons with Disabilities Act to MRDS' members.



Visit to Zoo Negara

MRDS and the Kiwanis Club of USJ jointly organized a visit to Zoo Negara. Eight MRDS families had the opportunity to bond with their family members in this activity.



11th International Symposium on Mucopolysaccharidosis (MPS) in Adelaide, Australia

Dato' Hatijah Ayob, the president of MRDS gave a talk on "Patients' Society – the Malaysian Experience" at the patients' society's session in this international symposium.



Book & Pamphlet Project

In 2010, MRDS started two projects with the aim of increasing public awareness and knowledge of rare disorders and as a means to raise funds. The first project is to publish a book about the experience and challenges of Malaysian families affected by rare disorders. The second project is to publish pamphlets containing medical information on 10 selected rare disorders.



Thank You!

MRDS wish to thank all who has given us their assistance in 2010. Without your helping hand, we will not be able to conduct our activities. We thank Ms NF Chin and Professor MK Thong who has diligently written MRDS' first book. Not forgetting the families who had come forward to be interviewed. Your brave spirit in sharing your story is commended. We wish to thank the Kiwanis Club of USJ who has given us their continual support and has again given a donation to us. MRDS needs your support in whatever form. Our numbers are not large. There are some of us who have journeyed far and some of us who are just beginning our journey. Let's all lend a hand to help.

MRDS Book - "Rare Journeys of Love"
Hot off the press – MRDS' first book entitled "Rare Journeys of Love" is out. It contains 10 stories of Malaysian families living with rare disorders. If you wish to purchase a copy, please call MRDS at 019-7714543 or attend our AGM on 9 June 2011, 5 pm at Hotel Armada, PJ. Alternatively, the book can be mailed to you. Please give us your name, address, contact number, e-mail address (if any) and payment of RM25 (RM20 book + RM5 postage within Malaysia) by cheque or postal order made out to 'Persatuan Penyakit Jarang Jumpa Malaysia' and mail it to 16, Lorong 5/10D, 46000 Petaling Jaya, Selangor.

1st Malaysia Conference on Rare Disorders
The 1st Malaysia Conference on Rare Disorders organized by MRDS will be held on 9-10 June 2011 at Hotel Armada, Petaling Jaya with the theme, 'Changing Mindsets and Transforming Lives'. It will be the first time in Malaysia that both the public and medical professionals are gathered in one place to discuss matters relating to rare disorders. Local and foreign speakers have been invited to talk on a variety of interesting topics. Members are encouraged to attend this seminar. The registration form can be downloaded from MRDS website.



PERSATUAN PENYAKIT JARANG JUMPA MALAYSIA (PPJJM)
(Malaysian Rare Disorders Society) (0064-07-WKL)
Mailing Address : 16 Lorong 5/10D, 46000 Petaling Jaya, Selangor
Tel: 019-7714543 Fax: 03-79588459
Website: www.mrds.org.my E-mail: info@mrds.org.my