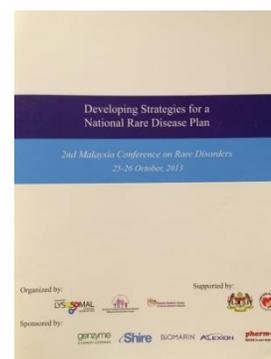




Group photo at the Rare Disease Day Malaysia 2014 Celebration with invited guest, Senator Bathmavathi (seated centre in yellow)

President's Message

In 2014, MRDS participated in a number of awareness events and organized talks for the benefit of patients and members. MRDS also worked together with Malaysia Lysosomal Diseases Association (MLDA) and the Malaysia Metabolic Society (MMS) to organize the Rare Disease Day Malaysia 2014 event. This followed from a successful 2nd Malaysia Conference on Rare Disorders organized by the coalition effort of the three societies in 2013. One of the recommendations was that patient groups should come together to speak with one voice. MRDS has rolled out the Conference report and we hope that it will spur parties to work together towards shaping a national rare disease plan that will benefit all rare disease patients.



Second Malaysia Rare Disorders Conference Report

Feb~ Rare Disease Day 2014

“Join Together for Better Care” was an apt theme for Rare Disease Day 2014 in Malaysia. MRDS, MLDA and MMS joined together for the first time to organize the Rare Disease Day event at Petaling Jaya Community Library on 22 March 2014. By joining together, we can deliver a more powerful message to a wider audience about rare disease. We express our gratitude to Senator Bathmavathi Krishnan who launched the event and her interest in getting to know about rare disease and rare disease patients.



From right: Dato' Hatijah with Dr Khahar (MRDS treasurer) & family and Tuan Zakaria & family during group discussion on Rare Disease Day 2014.

Apr~ Interview with Astro Awani Channel 501

Dato' Hatijah, MRDS president and Puan Sarina Hassan, MMS honorary secretary were both interviewed by local tv station, Astro Awani. They shared about the challenges and experiences faced when a loved one is diagnosed with a rare disorder. Puan Sarina's son, Mikail is diagnosed with mucopolysaccharidoses I (MPS I) while Dato' Hatijah's grand daughter had congenital disorders of glycosylation (CDG).



Dato' Hatijah's interview with Astro Awani.

May~ Talk on Phenylketonuria (PKU)

“When you have a special child, it’s something that you can never really prepare for but certainly an experience that’s anything but dull”, said Mr Chris Tan, a parent of a daughter with a metabolic disease called phenylketonuria (PKU). Mr Tan's talk was organized by MRDS with the Department of Molecular Medicine, University Malaya (UM). Mr Tan said that early detection and diagnosis for a rare disease is important to provide proper treatment to the patient before it is too late to reverse the debilitating effect of the disorder. After going through years of physiotherapy and rehabilitative treatment, his daughter, Tan Sin Li is now a confident and independent 38-year old.



(L-R) Dato' Hatijah, Mrs Tan, Mr Chris Tan and Sin Li at University Malaya.

June~ Annual General Meeting 2014

At the meeting, Puan Siti Norhayati Harun, the head of the Medical Social Work Department, UMMC was our guest speaker and she spoke on "Services of the Medical Social Work Department". The information given allowed members to understand the procedure and range of assistance provided by the department. Youth volunteers entertained the children with art and craft activities and a puppet show. We wish to thank Puan Siti Norhayati and her staff for their contribution towards the success of the meeting.



Dato' Hatijah presenting a token of appreciation to Puan Siti Norhayati Harun, the head of Medical Social Work Department after her presentation.

July~ Book launch – “I am a Zebra! Making Sense of a Rare Disorder”

“I am a zebra. Why? A zebra is a medical jargon used to describe an unpredicted diagnosis.” – Patsy Kam. Patsy Kam was referring to the title of her book that chronicled her 10-year journey dealing with paraganglioma, a rare disorder where tumours develop from neuroendocrine tissues. Dato' Hatijah was invited to write the foreword to her book.



Patsy Kam (right) at the launch of her book, "I am a zebra! Making sense of a rare disorder."

Aug~ Expedition Mount Kinabalu–Coalition Duchenne

Expedition Mount Kinabalu is an annual climbing event organised by Coalition Duchenne (a US NGO) to raise awareness of Duchenne Muscular Dystrophy (DMD). MRDS was able to send a representative to participate in the climb. Proceeds from the climb go towards research in DMD.

Sept~ Jeans4Genes Day

The students and lecturers of the Department of Biomedical Science, UM organized a Jeans for Genes Day programme to create awareness for children with genetic disorders. Among the activities were a wheelchair race, cupcake sale and a flash mob dance. The Alice Smith School also had a donation drive in their school during Jeans for Genes Day and donated part of the proceeds to MRDS.



Whew, the MRDS banner made it to the top of Mount Kinabalu at the DMD Awareness Kinabalu Climb.

Oct~ 2nd Malaysia Rare Disorders Conference Report

We are proud to announce the publication of the Report of the 2nd Malaysia Conference on Rare Disorders with the theme “Developing Strategies for a National Rare Disease Plan”. The report has been distributed to stakeholders and hopefully the recommendations contained therein will be acted upon.

Nov~ Visit to Cruise Ship

MRDS was invited by Club Rainbow Singapore to join a half day tour of the Royal Caribbean Cruises' ship, *Mariner of the Seas*. It was a good outing because all the members who came have not stepped foot (or been wheeled) on a cruise ship before. Members also connected with families affected with rare disorders from Singapore who were on board.



Dato' Hatijah interacting with UM students during Jeans for Genes day.



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Our generous donors



MRDS members taking a photo with lovable Po on board the cruise ship.