

President's Message

One of the long term objectives of MRDS is to see that every patient with rare disease has access to treatment, medication, therapy and other support services. MRDS has taken the first step towards this direction by organizing the 2nd Malaysia Conference on Rare Diseases where stakeholders were invited to discuss strategies to develop a national rare disease plan.

Rare Disease Day Celebration 2013

Rare Disease Day is an important date in the MRDS calendar as it is the one day specially set aside for rare disease patients and families. For 2013, MRDS travelled to Penang to organize an exhibition to create awareness of rare disease amongst visitors and staff at the Penang General Hospital and also to meet up with members living in the northern part of Malaysia. MRDS is grateful for the support provided by the Penang General Hospital and Dr Keng WT for a successful exhibition.

Participation in Events

MRDS started off the year by participating in an exhibition of the National Biomedical Science Gathering. This Gathering was organized by the biomedical science students of University Malaya (UM). In another event, MRDS was invited by the Medical Social Work Department of the National University of Malaysia Medical Centre (PPUKM) to participate in their Meet-the-Clients Day. Dato' Hatijah was also chosen to participate in a leadership course called the Facilitative Leadership Training for Social Change in Singapore.

Members' Outing to Petrosains, KLCC

Every year MRDS makes an effort to organize an outing for MRDS families. This year, the outing to Petrosains, KLCC was a joint effort between MRDS and the Medical Social Work Department of University Malaya Medical Centre (UMMC) with the theme 'Discovering Science with Family'. The event was attended by both MRDS families and families of the staff at the Medical Social Work Department. MRDS welcomes future collaboration with the Medical Social Work Department in similar community service projects.

MRDS Survey

MRDS conducted a survey on the common issues and problems faced by rare disease patients in Malaysia with the aim of presenting its findings at the 2nd Malaysia Conference on Rare Disorders. This is the first survey conducted by MRDS and MRDS would like to thank all members who had participated in the survey.

The preliminary results from the survey are as follows:

- i) 1 out of 3 patients waited more than a year to obtain a diagnosis. More than half of the patients had to meet three or more doctors before getting a diagnosis.
- ii) 2 out of 3 patients were advised to take medication and/or undergo surgery. A small number of patients cannot afford to go for treatment due to insufficient funds.
- iii) 3 out of 4 patients were advised to undergo some form of therapy but 1 out of 3 patients have stopped going for therapy.



MRDS President, Dato' Hatijah Ayob at the Penang General Hospital for the Rare Disease Day 2013 exhibition.



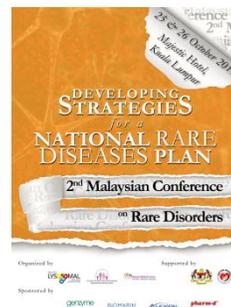
Dato' Hatijah having a discussion with Prof Dato Dr Raymond Azman Ali, director of PPUKM during Meet-the-Clients Day organized by the Department of Medical Social Work of PPUKM.



Members' outing to Petrosains, KLCC.



Puan Siti Norhayati, head of Medical Social Work Department of UMMC presenting a token of appreciation to Dato' Hatijah.



2nd Malaysia Conference on Rare Disorders booklet. The Conference was held at the Majestic Hotel, Kuala Lumpur.

- iv) Almost all patients suffered from some form of disability.
- v) 3 out of 10 patients had to spend more than 15% of their families' monthly income for treatment and care while 2 out of 10 families had to spend more than 20%. 1 out of 4 families had to make a major financial outlay for treatment.
- vi) 1 out of 3 patients needs help to pay for the treatment.

2nd Malaysia Conference on Rare Disorders

For the first time, three patient support groups on rare diseases, namely, MRDS, Malaysia Metabolic Society and Malaysia Lysosomal Diseases Association came together to jointly organise the Conference with the theme 'Developing Strategies for a National Rare Disease Plan'. More than fifty invited participants from the Ministry of Health (MOH) and other ministries, universities, the pharmaceutical industry, rare disease patient support organisations and other NGOs attended the Conference.

Local and foreign speakers from Australia and Taiwan were invited to speak on the following themes - developing strategies for a national rare disease plan; coordinated national activity; multidiscipline clinical care and systematic approach for rare disease patients; and on-time treatment. This was followed by roundtable discussions by the participants.

There was a general consensus by the participants that rare disease patients have rights founded on the Universal Declaration of Human Rights and other international conventions; that 'rare disease' should be given formal recognition; that rare disease patient support groups join together to form an alliance to speak with one voice; that there was an all-round support for the development of a national rare disease plan; and that a multi-stakeholder committee be formed to further explore and discuss matters raised during the Conference.

Annual General Meeting 2013

A new committee was elected in 2013. We welcome two new committee members namely, Ms. Nadeera Vasu and En. Shahrul Hafiz. After the AGM, our invited guest speaker, Dr Leong Huey Yin from the Ministry of Health spoke on medical genetic services provided by MOH.

Participation in fund raising events

MRDS would like to say a big thank you to all volunteers and organisations who organised fund raising events for the benefit of MRDS. The fund raising events were the TTDIGC Charity Carnival, Charity Walk organised by Dasein Academy of Art and the 'Feel Good Run 2013' organised by ntv7.



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Dato' Hatijah with the Deputy Director-General of Health (Medical), Datuk Dr S. Jeyaindran Tan Sri Sinnadurai during the press conference at the 2nd Malaysia Conference on Rare Disorders.



Participants at the 2nd Conference on Rare Disorders 2013.



Annual General Meeting of MRDS 2013.



MRDS stall at the "Feel Good" Charity Run 2013 organized by ntv7.

Thanks & Appreciation to:

Dr Azlina Ahmad Annuar, UM
 Penang General Hospital
 Dr Keng W T
 Department of Medical Social Work
 PPUKM
 Department of Medical Social Work
 UMMC
 Puan Siti Norhayati Harun
 University of Malaya Medical Centre
 Ministry of Health Malaysia
 Datuk Dr S. Jeyaindran Tan Sri
 Sinnadurai
 Invited speakers and guests at the
 2nd Malaysia Conference on Rare
 Disorders
 Dr Leong Huey Yin
 TTDIGC
 Lecturers & students of Dasein
 Academy of Art, KL
 ntv7
 Sponsors from the pharmaceutical
 industry that supported the 2nd
 Malaysia Conference on Rare
 Disorders and you, who took part
 in the MRDS survey.