Malaysian Rare Disorders Society

BERITA PPJJM 2024

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Message from the President

by Nadiah Hanim Abdul Latif

In 2024, the Malaysian Rare Disorders Society (MRDS) continued its mission of advocating for individuals and families affected by rare diseases across the nation. This year saw remarkable progress with expanded outreach programs, new partnerships with healthcare institutions, and increased public awareness through campaigns like Rare Disease Day Malaysia 2024. MRDS also played a pivotal role in pushing for better access to early diagnosis and treatment by engaging with policymakers and supporting research initiatives. With new support groups formed and educational workshops conducted nationwide, 2024 has been a year of growth, resilience, and hope for the rare disease community in Malaysia.

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Cri Du Chat Syndrome Chat



7th January 2024
The first family outing for Cri Du Chat Syndrome (CDCS) Malaysia at Titiwangsa Lake Park, Kuala Lumpur, was a valuable learning experience for everyone involved.

World Rare Disease Day

27th February 2024
Potluck picnic celebration held at The Top, Komtar Tower, Penang.

28th February 2024
Rare Disease Awareness Day was held from 8 a.m. to 1 p.m. at University of Malaya Medical Centre (UMMC), featuring informative and inspiring activities.

29th February 2024

- Rare Disease Day Celebration (9am - 12pm) - Main Lobby, Hospital Pakar Kanak-Kanak UKM.
- Rare Disease Day Celebration (9am - 12pm) Foyer B, Penang General Hospital.
- Rare Disease Day (9am - 3pm) Lobby, Main Wing (Block 3), Loh Guan Lye Specialists Centre
- (Closed Event) Rare Disease Day Celebration (2pm - 4:30pm) Perdana Auditorium, National Institute of Health, Setia Alam, Selangor
- Rare Disease Awareness Forum, National Institute of Health (NIH)
- Interview with Ms. Nadiah Hanim on “Adaptasi, Episode 9: Odisi Sebuah Transisi,” produced by Rubbertapper Production House (10:30 p.m., Berita RTM)
- Message from the Deputy Minister of Youth and Sports, YB Adam Adli Abdul Halim.



27TH FEBRUARY 2024

THE TOP, KOMTAR TOWER.





28TH FEBRUARY 2024

UMMC.









29TH FEBRUARY 2024

PENANG GENERAL HOSPITAL.



29TH FEBRUARY 2024

HOSPITAL PAKAR KANAK-KANAK UKM.





29TH FEBRUARY 2024

LOH GUAN LYE SPECIALISTS CENTRE.









29TH FEBRUARY 2024

RARE DISEASE AWARENESS FORUM - NATIONAL INSITUTE OF HEALTH (NIH)



29TH FEBRUARY 2024

INTERVIEW IN BERITA RTM



29TH FEBRUARY 2024

MESSAGE FROM YB ADAM ADLI

Featured on Mapping Rare

1st March 2024 - Our President, Nadiah Hanim Abdul Latif, represented MRDS, showcasing our dedicated efforts to combat stigma and raise awareness about rare disorders in Malaysia. MRDS was proudly featured as one of the first Patient Advocacy Groups (PAGs) on Mapping for Rare.



Fun Walk

7th Mar 2024 - Continuing the spirit of Rare Disease Day, MRDS took part in the Fun Walk on March 7, 2024, organized by the Social and Welfare Club of the JKM Johor Main Office. Representing MRDS was Secretary and Southern Region representative, Mr. Zakaria Shah, who delivered a heartfelt sharing on Rare Diseases—highlighting the challenges of stigma and the importance of societal acceptance for individuals and families affected by these conditions.









Roundtable Discussion on Advocacy & Communication in Rare Disease Strategy

10th March 2024 - The round table discussion on Advocacy and Communication in Rare Disease Strategy, spearheaded by the Galen Center for Health and Social Policy, highlighted the pressing need to integrate treatable rare diseases into the current but limited newborn screening (NBS) program in Malaysia. Dr. Azrul Mohd Khalib provided a comprehensive summary of the insights gathered from the recent 'New-born screening, Rare Diseases, and Public Policy workshop,' emphasizing the significance of an expanded NBS program as a cost effective measure in rare disease management. Additionally, Dr. Rozita Abdul Rahman's (a Public Health Physician from the Family Health Development Division at the Ministry of Health) presentation of the success story of the current but limited NBS program, provided some understanding on the program outcomes alongside its learnings which potentially can be used when planning for the expanded NBS program.





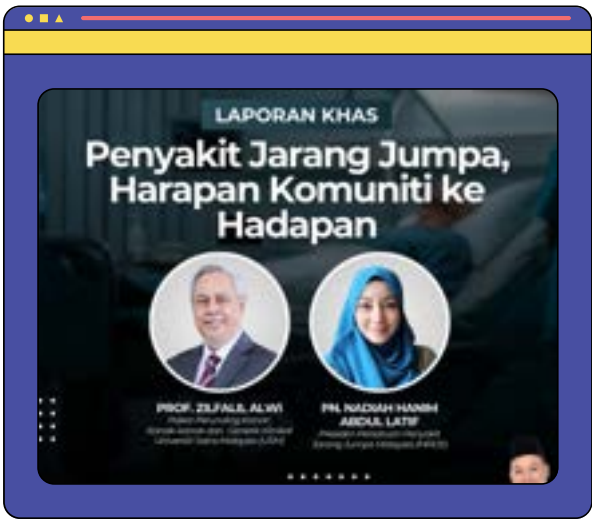
2nd Asia Pacific Rare Disease Summit 2024

18th Mar 2024 - During the Summit, MRDS President Puan Nadiah Abdul Latif joined representatives from rare disease organizations in Thailand, Singapore, Indonesia, and the Philippines on stage. Together, they discussed key topics including "Patient Empowerment as a Critical Driver to Maximize Capacity in Patient-Centric Access Policy" and "Unveiling Southeast Asia 5-Year Patient Organization Plan."





IKIM.fm Spotlights Rare Diseases in Special Radio Feature



19th March 2024 - Special report titled *"Penyakit Jarang Jumpa, Harapan Komuniti ke Hadapan,"* featuring Prof. Zilfalil Alwi and Ms. Nadiah Hanim Abdul Latif, was presented by Ahmad Nazri Mohd Yusof on IKIM.fm (91.5FM in the Klang Valley).

"Suara Kita" Workshop

23rd March 2024 - We benefited from the 'Policy Making & Budgeting' workshop by Vriens & Partners and Dr. Dinesh from the MOH Health Transformative Unit, organized by Hemophilia Society of Malaysia and supported by Roche Malaysia. Additionally, the screening of a documentary on cancer screening and patient navigation for cancer patients in rural Sarawak, a project by SCAN (Society For Cancer Advocacy and Awareness Kuching) highlighted best practices for serving local communities.









World DNA Day Celebration

24th-25th April 2024 - The World DNA Day celebration at Dataran Kelabu, School of Medical Sciences, Universiti Sains Malaysia (USM), Health Campus, Kubang Kerian on April 24 & 25 saw participation from various stakeholders including service providers of Allied Health, Non-profit organizations, related companies/industries and local high school students. The event featured many activities including career talks and project competition (i.e., TikTok video competition with the theme of human genetics) aimed at fostering interest in human genetics among students and the general public. Hands-on activities, including viewing actual chromosomal pairs couple with an interactive session on human chromosomes, provided an enriching experience over the two-day event. This event was organized by Human Genome Centre USM, in collaboration with Malaysian Society of Human Genetics (MSHG) & Genomics & Life Sciences Research Cluster in School of Medical Sciences, USM.









World Health Assembly 77th Side Event



29 May 2024 - Malaysian Rare Disorders Society's maiden representation to the World Health Assembly 77th side event on rare diseases in Geneva. A multicountry engagement led by Rare Disease International with the mission to engage WHO member states to advocate for Universal Health Coverage and equity for individuals living with rare diseases (PLWRD) as a continuation and fortification of commitment since the adoption of the UN Resolution for Persons Living with a Rare Diseases. The milestone was made more meaningful with the Ministry of Health, Malaysia agreeing to co-host the event alongside France, making it our second key international collaborative engagement with the Ministry since UNGA78, New York in 223.

Rai Ummah Program: Engagement Session with the Deputy Minister at the Prime Minister's Department (Religious Affairs)

5th June 1024 - Yayasan Dakwah Islamiah Malaysia (YADIM) invited MRDS to attend the Rai Ummah program: a friendly session and dialogue with the Deputy Minister in the Prime Minister's Department (Religious Affairs), YB Senator Dr. Zulkifli Hasan, alongside Muslim NGOs for Persons with Disabilities (OKU) and OKU units from public universities.







Yayasan Hasanah Session

5th June 2024 - We thank Thrivewell, MIASA Malaysia and Yayasan Hasanah for organising this round of ilmu hasanah and for MRDS to moderate the session. Thank you to everyone who joined us for a chat with Dr. Ahmed Hankir, a renowned consultant psychiatrist, advocate, and researcher. Dr. Ahmed's insights on dismantling mental health stigma and supporting recovery journeys were invaluable.

MRDS President Elected to Rare Diseases International Council

19th June 2024 - MRDS is proud to announce that our president, Nadiah Hanim Abdul Latif, has been elected as a new council member of Rare Diseases International (RDI), at the RDI Annual General Assembly yesterday. She will join an international team dedicated to serving the global rare disease community.



NADIAH HANIM ABDUL LATIF
MRDS PRESIDENT

Children's Workshop

13th June 2024 - The collaborative effort between AstraZaneca and MRDS was kicked-off with the Bahasa Malaysia translation of a children's book entitled "Zara Shares Her Stripes - A story about accepting your rare condition", followed by the book first children workshop on accepting differences and being kind. We have also started the distribution of the book to hospitals and education centers.









Expedition Mt Kinabalu - Coalition Duchenne

13th-15th June 2024 - Over the past twelve years, around 700 hikers have scaled Mount Kinabalu as part of an annual expedition organized by Catherine Jayasuria of Coalition Duchenne. The Expedition Mount Kinabalu, aims to raise awareness and funds for individuals living with Duchenne Muscular Dystrophy (DMD). Today, Coalition Duchenne provides support to boys with DMD around the globe including Sabah, working closely with Dr. Heng Hock Sin, a Pediatric Neurologist at Hospital Wanita dan Kanak-Kanak Sabah in Kota Kinabalu.







Mesyuarat Agung Tahunan (AGM) PPJJM 2024

22nd June 2024 - PPJJM held the 17th MRDS AGM in a hybrid format, with members attending physically at Twenty Tree Boutique Hotel, Shah Alam, and online via Zoom, marking the first time in four years that the AGM was not held entirely online.



Parliamentarians' Regional Meeting Preparedness and Care Economy Kuala Lumpur



Nadiah Hanim Abdul Latif highlighting the efforts of MDRS.

18th July 2024 - Nadiah Hanim Abdul Latif from Malaysian Rare Disorder Society (MRDS) delivered an insightful speech on the global challenge of rare diseases, affecting approximately 300 million people worldwide with over 7,000 rare conditions, of which about 95% lack treatment. Notably, 70% of these conditions start in childhood, leading to significantly higher medical costs for those affected.

She highlighted the efforts of MRDS, which has over 320 members, more than 30 support groups, and work with 18 registered societies (related to rare disease) addressing different rare diseases. MRDS focuses on creating a supportive ecosystem through newborn screening, genetic testing, medical treatment, and connecting families in crisis to necessary care.

Nadiah emphasized MRDS's active engagement at local, regional, and international levels, including participation at the UNGA78 on UHC for Rare Diseases and co-hosting the 2023 APARDO conference in Kuala Lumpur. These engagements aim to advocate for better healthcare access and universal health coverage for people living with rare diseases (PLWRD).



Nadiah Hanim Abdul Latif outlining MDRS's strategy for 2024-2026.

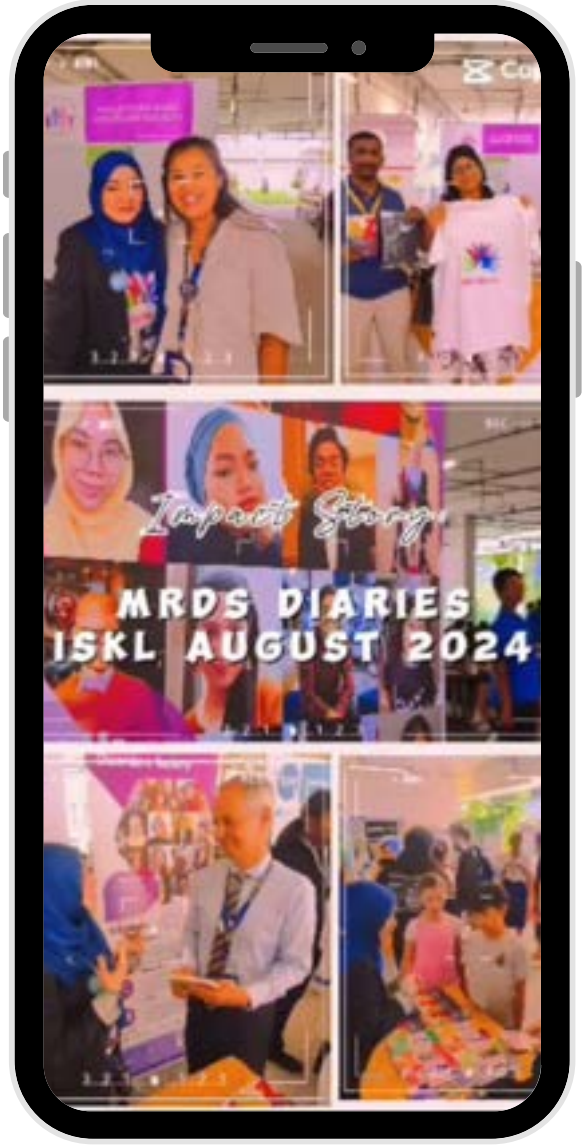
She outlined MRDS's strategy for 2024-2026, which includes advocating for quality healthcare, inclusive education, and employment opportunities for the rare disorders community in Malaysia. Collaborating with stakeholders and the government, MRDS aims to drive the formulation and implementation of inclusive national policies and action plans.

Nadiah also addressed the economic burden faced by families due to high treatment costs, limited resources, lack of insurance coverage, and the overall impact on the national economy. She stressed the importance of multi-stakeholder collaboration to set up patient groups and support their growth, and highlighted the efforts towards establishing a National RD Policy and securing an annual national budget for rare diseases.

Online Session: Challenges and Hopes in Rare Diseases



7th August 2024 - MRDS was invited to share in an online session on the topic of "Penyakit Jarang Jumpa: Cabaran dan Harapan" (Rare Diseases, What Are the Challenges and Hopes?) organised by the Pejabat Pembangunan Wanita Negeri Selangor. In this informative sharing session, which lasted for nearly an hour and a half, Mrs. Nadiah Hanim (President of MRDS) began by introducing the Rare Disease Community, the role of MRDS, and delving further into the challenges faced by families and individuals with rare diseases. The session concluded with an interactive Q&A segment.



ISKL Community Service Partners Awareness Fair

23rd August 2024 - Team MRDS had the privilege of participating in the ISKL Community Service Partners Awareness Fair. The half-day program kicked off with an insightful briefing about ISKL, which we attended alongside an eager audience. We were then thrilled to set up our exhibition booth, where we met with passionate ISKL students who were eager to learn more about rare diseases.





MCAPS Asia Finance Summit FY25: Together We Grow

27th-29th August 2024 - We were pleased to highlight the hard work of the Malaysian Rare Disorders Society (MRDS) in breaking barriers and improving the lives of families affected by rare diseases, as shared by MRDS President, Nadiah Abdul Latif. Equally inspiring were the stories shared by Miza Marsya and Linda Rao who opened up about their personal journeys, the challenges they face, and the actionable steps the public can take to make a difference including supporting MRDS platforms.





MyGenom Launch Event

29th August 2024 - As part of the ongoing efforts to amplify the voices of the RD Malaysia community, the MRDS Team had the opportunity to attend the MyGenom Launch Event on August 29, 2024. This event marks a significant milestone in the advancement of genetic research and healthcare in Malaysia, particularly in the field of genomic sequencing technology. The event was officiated by the Minister of Health, Datuk Seri Dr. Dzulkefly Ahmad, alongside the Minister of Science, Technology, and Innovation (MOSTI), Chang Ling Kang. During the event, the government expressed its intention to collect 10,000 genomic sequences through the MyGenom Project, aiming to produce an accurate reference for local genetics to enhance healthcare delivery.



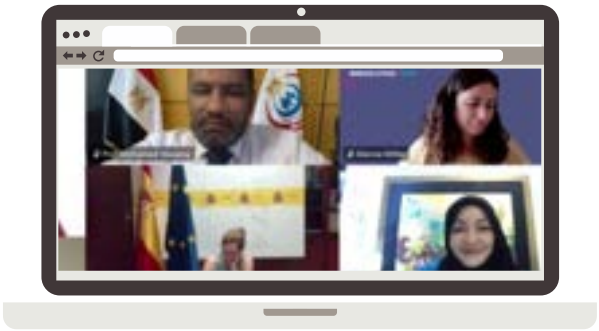


Collaboration with Cancer Research Malaysia (CRMY)



30th August 2024 - The Malaysian Rare Disorders Society (MRDS) is excited to collaborate with Clinical Research Malaysia (CRM) to enhance patient access to rare disease clinical trials, ultimately enhancing treatment options for our community.

Public Webinar: Towards a WHA Resolution on Rare Diseases 2025



30 August 2024 - Nadiah Hanim Abdul Latif, the Malaysian representative, who is also the President of MRDS, delivered a speech expressing support for the resolution on Rare Diseases to be presented in 2025.

Townhall Session with the Minister of KPWKM



3rd September 2024 - The MRDS Team attended the Townhall Session with the Minister of KPWKM, YB Dato' Sri Hajah Nancy Shukri. During this important session, in the Q&A and suggestion segment, Puan Nadiah Hanim raised several key issues related to the RD Community concerning the KPWKM ministry.

SMA Awareness - Genetic Testing and Management (Webinar)



7th September 2024 - Strand Life Sciences Pvt Ltd, in collaboration with MRDS and Spinal Muscular Atrophy Malaysia, hosted an insightful webinar on SMA Awareness: Genetic Testing and Management. The session brought together experts from Malaysia and India, offering valuable insights into Spinal Muscular Atrophy (SMA) and its latest advancements in diagnosis, treatment, and patient care.

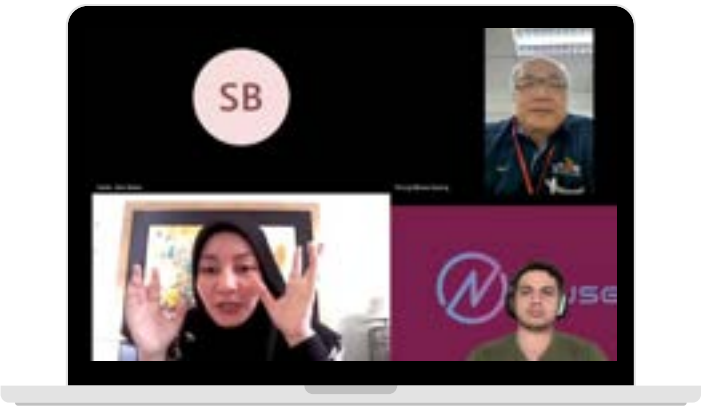
Dialog Belanjawan 2025





9th September 2024 - MRDS President Nadiah Hanim Abdul Latif represented the organization at the Dialog Belanjawan 2025 with the Honourable Minister of Health at The Everlyn Hotel, Putrajaya. During the session, MRDS highlighted key issues affecting rare disorder (RD) patients, including the need for nationwide newborn screening to reduce costs, public-private collaboration to raise RD awareness in rural areas, improved access to precision medicines and genetic services, and enhanced support for teaching hospitals and geneticists.

Health Data Awareness Webinar: Your Right



14th September 2024 - MRDS and Nexuses held a public webinar titled "Health Data Awareness: Your Right." This engaging discussion was filled with valuable information that can help individuals with RD and their families better manage their health.

Featured on The Thriving Misfits Podcast



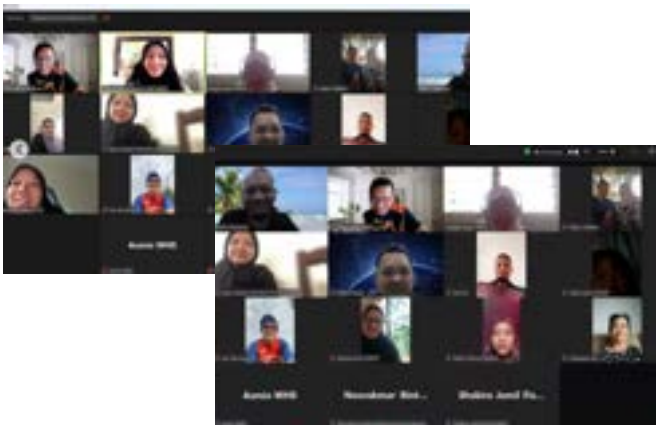
22nd September 2024 - MRDS was featured in the latest episode of The Thriving Misfits Podcast. The episode, titled “Rare but Resilient: Celebrating Diversity Through the Lens of Rare Disorders” (Episode 18), included MRDS President Nadiah Hanim Abdul Latif and rare diseases advocate Eleanor Johnson.

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Hi Komuniti RD Malaysia





28th September 2024 - MRDS held the Hi Komuniti RD Malaysia session, which was attended by nearly 25 representatives from NGOs and support groups. During the meeting, MRDS shared the latest updates regarding government meetings and current developments of Orphan Drugs in Malaysia.
Six key focus areas for Rare Diseases in Malaysia for 2025 were discussed: inclusive education, national policy, caregiver support, data registry, youth empowerment, and equitable treatment.

Talk at Taylor's University

16 October 2024 - As part of our efforts to build a more comprehensive ecosystem for rare diseases, MRDS President, Ms. Nadiah Hanim, was invited earlier this month to deliver a lecture to students of the Intro to Sociology course at Taylor's University.







Meeting with Members of the Special Select Committee on Health

16 October 2024 - We applaud the effort by Kementerian Kesihatan Malaysia for the formulation of the National Rare Disease Policy which release is targeted by year end.







RDI Membership Meeting 2024 in Barcelona

21st-22nd October 2024 - The President of MRDS proudly represented Malaysia at the RDI Membership Meeting in vibrant Barcelona, connecting with delegates from 31 countries.







Day 1, Session2: Member Presentations and Priorities



Day 1, Session 3: Driving Active Engagement to Improve Outcomes for PLWRD



Day 2: Aurora Awards Dinner



Day 2 Session 7: RDI Framework to Improve PLWRD Quality of Life



23 October: Visit to Sant Joan de Déu - Barcelona Children's Hospital

RIE Partnership Dinner

25th October 2025 - The MRDS team was honoured to attend the RIE Partnership Dinner at MAHSA University held at MAHSA's main campus in Bandar Saujana Putra, Selangor.



World Orphan Drug Congress Europe 2024

23rd-25th October 2024 - Continuing the advocacy and collaboration mission of MRDS this year, the President of MRDS participated in the World Orphan Drug Congress Europe 2024, held at Fira de Barcelona Montjuïc.









"Sesi Libat Urus Bersama Golongan OKU, Mantapkan Aspek Inklusiviti PPPTM 2025 - 2035

24th October 2024 - Following the engagement session with persons with disabilities (PWD), MRDS is excited for the progress of the comprehensive 10-year development plan for Malaysian higher education. This Work-In-Progress plan embraces the principle of #NoOneIsLeftBehind and aligns with the spirit of Malaysia MADANI.





Collaborative Discussion with YB Danial Al Rashid Haron

9th November 2024 - Thank you, Assoc. Prof. Dr. Wan Puspa Melati Wan Halim, Principal Researcher – Healthcare and Cost of Living, for including the rare disease community in this important collaborative discussion, chaired by YB Danial Al Rashid Haron, aimed at shaping inclusive and impactful policies for people with disabilities (OKU) in Selangor.





Star Golden Hearts Award

12th November 2024 - Prof. Thong MK was selected as one of the ten recipients of the prestigious Star Golden Hearts Award, chosen from over 500 remarkable nominations! This award celebrates NGOs and individuals whose tireless work uplifts communities, and Prof. Thong's unwavering dedication to the rare disease community is truly inspiring.







Rare Disease Awareness Day 2024

14th November 2024 - Prof. Datin Dr. Norlinah Mohamed Ibrahim and her dedicated team at Fakulti Perubatan UKM successfully organized a meaningful and impactful Rare Disease Awareness Campaign.







Genetic Counselor Awareness Day Celebration

15th-16th November 2024 - **The** Genetic Counselor Awareness Day Celebration was held for the first time with great enthusiasm at Gurney Walk, Penang. This two-day program was organized by Genetic Counseling Society Malaysia (GCSM) in collaboration with Genetic Clinic, Hospital Pulau Pinang.



Spastic Fun Run

17th November 2024 - MRDS participated in the 29th Annual Spastic Fun Run held at Dataran Merdeka, Kuala Lumpur. The event, organized by SCAS & FT, attracted around 2,000 participants including Datuk Seri Nancy Shukri, who raised important questions about the needs of individuals with rare diseases—highlighting not only their physical and nutritional requirements but also the critical role of caregivers.





MyPOPI 10th Anniversary Gala Dinner

30th November 2024 - MRDS was honoured to be invited to join MyPOPI team on the 10th Anniversary Gala Dinner celebrating their dedication to safeguarding the welfare of individuals and families affected by Primary Immunodeficiency (PID) in Malaysia.



Yayasan Sime Darby (YSD) International Persons With Disabilities Day Celebration

4th December 2024 - The Yayasan Sime Darby (YSD) International Persons With Disabilities Day celebration on December 4th offered yet another powerful platform for the Malaysian Rare Disorders Society (MRDS) to spotlight its 20-year journey advocating for the rare disease community. In an engaging and insightful sharing session, MRDS explored innovative initiatives by the Ibnu Ummi Maktum Research Center, USIM, whose team is developing an app that serves as a one-stop resource center for the PWD, and EmployAble Malaysia, which champions employment with dignity for individuals with disabilities. These initiatives align with the shared vision of creating a world where people with rare disorders and disabilities can truly thrive.







Newborn Screening in Malaysia: Moving Forward

10th December 2024 - The Department of Paediatrics, Faculty of Medicine, Universiti Kebangsaan Malaysia (UKM) organized the Seminar & Forum on Newborn Screening at the UKM Specialist Children's Hospital. This one-day program brought together leading experts to discuss the landscape of newborn screening in Malaysia, covering both rare diseases (RD) and non-rare diseases, along with the challenges faced in



the cultural, geographical, and socio-economic contexts. The Forum titled “Newborn Screening in Malaysia: Moving Forward,” chaired by Puan Nadiah Hanim Abdul Latif, President of MRDS, addressed key issues including structural challenges, operational dynamics, and market factors. The panel also discussed strategies to prioritize and expand newborn screening in Malaysia, shared lessons learned, and explored how regional collaborations can be leveraged for improvement. The panel acknowledged that existing silos in efforts often hinder progress. It was agreed by all that an effective ecosystem can only be achieved if all stakeholders are actively involved.



“Transitioning Years: A Caregiver’s Journey” Webinar

20th December 2024 - MRDS hosted a public webinar from the Hi, Malaysian RD Community series titled Transitioning Years: A Caregiver's Journey, specially dedicated to caregivers of RD (Rare Diseases) and persons with disabilities (PWD). The session featured three fathers of RD and PWD individuals.



