

inside THE ISSUE

Recognizing the 49
Outstanding Newborn
Screening Facilities in NCR

2

NBS Stakeholders
Meeting Reinforces
Commitment to “Walang
Maiwang Pasyente at
Pamilya”

2

215 Health Facilities
Unite for NBS Program
Implementation Review
in SOCCSKSARGEN

4

“Safe ba ang Anak Ko?”
Webinar Highlights
Importance of Early
Detection for Rare Diseases

5

DOH-CALABARZON
Strengthens NBS Programs
Through Regional
Alignment Meeting

6

Lighting the Way for
Rare Disease Awareness
in 2026

7

DOH Convened 2026
National Rare Disease
Forum

8



Philippine National Scientist Dr. Carmencita Padilla addresses delegates during the 8th Workshop on Consolidating Newborn Screening Efforts in the Asia Pacific Region in Hanoi, Vietnam, where regional leaders and experts gathered to strengthen collaboration and advance universal newborn screening across Asia-Pacific.

Uniting the Region for Every Newborn: Asia-Pacific Strengthens Collaboration on Newborn Screening in Hanoi

Across the Asia-Pacific Region, newborn screening continues to stand as one of the most effective public health interventions for preventing lifelong disability and early childhood mortality.

This shared commitment came into focus in Hanoi, Vietnam, as leaders, experts, and program implementers gathered for the 8th Workshop on Consolidating Newborn Screening Efforts in the Asia Pacific Region, held from January 12–16, 2026.

Bringing together representatives from Bangladesh, Cambodia, India, Indonesia, Laos, Mongolia, Myanmar, Nepal, Pakistan, the Philippines, and Vietnam, along with international experts from the United States, Europe, and Singapore, the workshop served as a dynamic platform for collaboration, learning, and forward planning for regional newborn screening programs.

At its core, the workshop reaffirmed a simple but powerful principle: every newborn deserves a healthy start in life.

Through formal sessions, delegates engaged in intensive knowledge exchange. Country reports provided a comprehensive overview of national newborn screening systems, including coverage rates, sustainability strategies, and ongoing programmatic gaps. The country representatives shared their progress, challenges, and innovations in expanding screening coverage. While some nations have made significant gains, others continue to face structural and resource-related barriers, highlighting the need for stronger regional cooperation.

Expert-led lectures and moderated discussions focused on key technical and policy issues such as laboratory quality, program expansion, ...*Continued on page 3*

Recognizing the 49 Outstanding Newborn Screening Facilities in NCR

The Newborn Screening Center - NIH proudly announces and celebrates the 49 Newborn Screening Facilities (NSFs) from the National Capital Region (NCR) that achieved an outstanding performance rating for 2025!

The top-performing facilities were awarded certificates of appreciation for consistently meeting and exceeding critical life-saving benchmarks as follows:

- Maintaining an Unsatisfactory (Unsat) Rate of <1%.
- Achieving an Average Age at Collection of only 1–2 days.
- Ensuring an Average Transit Time of just 2–3 days.

Behind these statistics are dedicated healthcare professionals who understand that time is of the essence. By ensuring proper blood sample collection, securing accurate patient data, and prompt delivery, these NSFs ensure that every baby gets the best possible start in life.

Congratulations to our 2025 awardees! We look forward to seeing even more facilities join this prestigious list in the coming year.

NFVictorio

2025 TOP PERFORMING NEWBORN SCREENING FACILITY IN NCR

CODE	NEWBORN SCREENING FACILITY
8	MARY CHILES GENERAL HOSPITAL
56	HOSPITAL OF THE INFANT JESUS
300	SOUTH SUPER HIGHWAY MEDICAL CENTER
373	CATTLEYA LYING-IN CLINIC
480	DOÑA MARTA LYING-IN
582	OSPITAL NG PARANAQUE
60	FMC MOONWALK MIDWIFERY CLINIC
659	MARTINEZ MEMORIAL HOSPITAL
690	DE OCAMPO MEMORIAL MEDICAL CENTER
739	CALOOCAN CITY MEDICAL CENTER
768	OSPITAL NG SAMPALOC
780	NODADO GENERAL HOSPITAL
855	OSPITAL NG TONDO
960	BANGKAL LYING-IN CLINIC
98	FAIRVIEW GENERAL HOSPITAL
127	ANGELIC MATERNITY AND CHILD CARE CENTER
1337	ISABELA MIDWIFE CLINIC
1706	A. ELADIA BIRTHING AND MIDWIFE CLINIC
171	CUTA'S MIDWIFE CLINIC
173	RYLA & MICAH LYING-IN CLINIC
2142	KAMUNING LYING-IN CLINIC
2143	BETTY GO BELMONTE LYING-IN CLINIC
2236	BABY BUMP MATERNITY CLINIC
2364	DR. JEANETTE A. CATAPANG-COMBATE OB-GYNE CLINIC AND LYING-IN
3075	PASO DE BLAS LYING-IN CLINIC
3100	VILLON-TANSINSIN HOSPITAL, INC.
3123	GOOD SHEPHERD CHILDREN'S MEDICAL AND MATERNITY CLINIC
3298	VILMA L. MARIANO LYING-IN CLINIC
335	SUAZO MENDOZA LYING-IN CLINIC
3750	BAGBAGUIN HEALTH CENTER
4250	GRACEJAYNE LYING IN CLINIC
4994	MOTHER DEAR MEDICAL CLINIC
5737	ACG BIRTHING HOME AND DIAGNOSTIC LABORATORY, CO.
574	NAVOTAS CITY HOSPITAL
5813	POLO LYING IN CLINIC
612	NATIONAL GOVERNMENT CENTER LYING-IN CLINIC
6253	NAGPAYONG SUPER HEALTH CENTER LYING-IN
6424	CNMC CALOOCAN CITY NORTH MEDICAL CENTER
6917	UHA MATERNITY LYING-IN CLINIC
6988	OSPITAL NG MALABON
7172	ROSARIO MACLANG BAUTISTA GENERAL HOSPITAL
7377	CJM BIRTHING HOME
7570	VALIENTE'S MATERNITY CLINIC
7828	N.M. BIRTHING CLINIC
7839	GENTLEBIRTH LYING-IN CLINIC
7849	OSPITAL NG PARANAQUE DISTRICT II
7892	BIRTH BLESSED MATERNITY CLINIC
8000	SEVENBEDS MATERNITY CLINIC
8160	KAWAYANAN LYING-IN & MEDICAL CLINIC

NBS Stakeholders Meeting Reinforces Commitment to "Walang Maiiwang Pasyente at Pamilya"

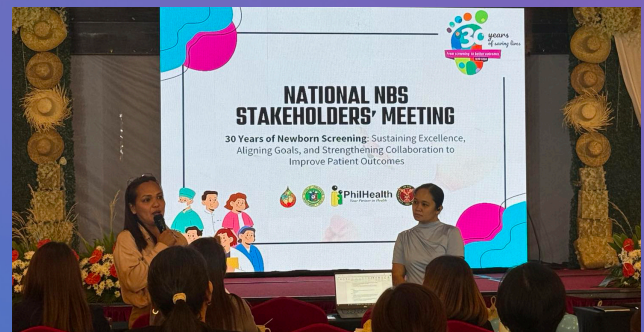
For three decades, the Philippines' Newborn Screening (NBS) Program has quietly transformed public health—detecting life-threatening conditions at birth and giving thousands of children a fighting chance for a normal life.

From January 27 to 30, 2026, this legacy took center stage at the National NBS Stakeholders' Meeting held in Binondo, Manila that brought together key players united by a single mission: "Walang Maiiwang Pasyente at Pamilya."

The gathering was more than a celebration—it was a strategic convergence of minds committed to sustaining excellence and improving patient outcomes. With both onsite and online participation, the meeting highlighted how collaboration remains the backbone of the program's success. As emphasized by NSRC Director Dr. Leilanie Nicodemus, the impact of newborn screening lies not only in early detection but in the continuity of care that follows.

Recent updates reflect both progress and evolving challenges. NBS coverage reached an impressive 98% in 2024, signaling near-universal access, though slight declines in 2025 reflect the need for sustained efforts. Policy developments, including the revised Expanded Newborn Screening (ENBS) fee and expanded coverage for confirmatory testing and patient monitoring, aim to strengthen equitable access to essential services. These changes reinforce a system that not only detects conditions early but also supports patients throughout their care journey.

Across regions, innovation and best practices are reshaping service delivery. From Region IV-A's improved recall rates through home visits and social welfare partnerships, to Bataan's fully integrated NBS Continuity Clinic model, local initiatives ... *Continued on page 3*



Nurse Jhonalyn D. Bantigue shares her challenges as a continuity clinic nurse of the newborn screening program.



An open forum gave stakeholders the opportunity to freely discuss their fears, challenges, and hopes, enabling providers to design more responsive and compassionate services.

Continued from page 2... demonstrate how community-driven approaches can bridge gaps in care. Meanwhile, multidisciplinary clinics in Mindanao and strengthened funding mechanisms in Visayas and Bicol highlighted the importance of accessibility, coordination, and financial support in improving compliance and long-term outcomes.

Beyond systems and policies, the meeting underscored a critical truth: healthcare is ultimately human. Workshops on empathy mapping reminded stakeholders that families are not just cases, but partners in care. Understanding their experiences, their fears, challenges, and hopes enables providers to design more responsive and compassionate services.

Looking ahead, the program faces both opportunities and demands. Strengthening referral networks, improving data systems, addressing workforce gaps, and preparing adolescents for transition to adult care are key priorities. The continued expansion of research, training, and partnerships signals a future where the NBS Program becomes even more integrated, inclusive, and patient-centered.

Thirty years on, the message is clear: newborn screening is not just a test—it is a lifelong commitment. And as stakeholders align goals and strengthen collaboration, the vision remains steadfast—no child left behind, no family unsupported, and every life given the chance to thrive.

JMCBautista



Representatives from Bangladesh, Cambodia, India, Indonesia, Laos, Mongolia, Myanmar, Nepal, Pakistan, the Philippines, and Vietnam, along with international experts from the United States, Europe, and Singapore, during the 8th Workshop on Consolidating Newborn Screening Efforts in the Asia Pacific Region in Hanoi, Vietnam.

Continued from page 1... and health system integration. A key highlight of the sessions was the collaborative drafting of the Hanoi Declaration, a regional commitment that will guide newborn screening efforts over the next 18–24 months.

Participants also visited the Vietnam National Children's Hospital, offering firsthand insight into clinical and operational practices in one of the region's active screening environments. The workshop extended beyond formal sessions to include networking activities and courtesy meetings designed to strengthen institutional relationships. These interactions provided space for countries to explore future collaborations, share technical expertise, and reinforce commitment to collective progress.

The Hanoi Declaration: A Shared Roadmap for Action

A key milestone of the workshop was the adoption of the Hanoi Declaration. Rooted in global child health frameworks, including the UN Convention on the Rights of the Child and World Health Organization resolutions, the declaration outlines 10 strategic action areas for advancing newborn screening in the region.

These include:

- Expanding regional collaboration and data sharing
- Strengthening national policies and legislation
- Advancing research to guide program development
- Improving sustainable financing mechanisms
- Institutionalizing newborn screening within

public health systems

- Building a skilled and sustainable workforce
- Ensuring quality assurance and program monitoring
- Improving access to treatment and long-term care
- Enhancing data systems and digital integration
- Strengthening advocacy and public awareness

Together, these commitments provide a clear and actionable framework for countries striving toward universal newborn screening coverage.

The workshop concluded with a strong sense of shared responsibility and renewed momentum. Delegates recognized that while challenges remain, particularly in expanding coverage and sustaining programs, the region is better positioned than ever to move forward through collaboration.

As participants departed Hanoi, the message was clear: newborn screening is not an isolated national effort but a regional commitment to equity, health, and survival.

The 8th Workshop on Consolidating Newborn Screening Efforts in the Asia Pacific Region stands as a milestone in strengthening partnerships and advancing a future where every newborn in the region has access to early detection, timely care, and a healthier life ahead.

VGMendoza



215 Health Facilities Unite for NBS Program Implementation Review in SOCCSKSARGEN

The Department of Health–Center for Health Development (DOH-CHD) SOCCSKSARGEN is strengthening its push for universal newborn care through a series of regionwide implementation review and strategic planning workshops that gathered healthcare workers, hospital representatives, and newborn screening coordinators from February to March 2026.

Dubbed “Strengthening Partnerships: Newborn Care Program (NCP) Implementation Review and Strategic Planning Workshops,” the four-batch activity brought together participants from Sarangani and General Santos City, South Cotabato, Sultan Kudarat, and Cotabato Province to assess program performance, address operational challenges, and map out strategies for 2026.

A total of 215 government and private hospitals, birthing homes, and lying-in facilities participated in the workshops, reflecting the region’s growing commitment to improving newborn care services and ensuring that no infant is left behind.

The initiative comes as SOCCSKSARGEN surpassed the Department of Health’s expanded newborn screening target in 2025, recording an unofficial coverage rate of 103.28%. The achievement exceeds the national goal of reaching 95% expanded newborn screening coverage by 2030 under the Universal Health Care Law.

For health officials, the milestone highlights both the progress made and the need to sustain high-quality screening and referral systems. “The success of newborn care in our region relies on collaboration, adherence to standards, and a shared responsibility to ensure no newborn is left behind,” said Rohainnah M. Mua, Newborn Care Program Manager, in her opening remarks.

The workshops served as a platform for frontline healthcare providers, including nurses, midwives, clerks, and facility owners, to review existing policies, share best practices, and formulate facility-specific action plans aimed at improving newborn screening services. Participants also received technical updates from partner institutions involved in newborn care and screening.

Perly F. Bermudez, of Newborn Screening Center (NSC)-Mindanao, emphasized the importance of specimen quality and timely submission of samples to avoid delays in diagnosis. “Timely submission and proper collection of specimens are critical to reducing delays and ensuring accurate results,” Bermudez said.

Dr. Maria Christina Bondoc-Eran of the NBSCC–Cotabato Regional and Medical Center underscored the importance of strong referral systems for newborns with confirmed conditions, while Dr. Sheila May Pandan of PhilHealth XII clarified policies concerning claims for the Enhanced Newborn Care Package, particularly for referred newborns delivered within 24 hours.



Participants actively engage in the Newborn Care Program Implementation Review and Strategic Planning Workshop, sharing insights and recommendations to strengthen collaboration and improve the delivery of newborn care services.

Specialized discussions on inborn errors of metabolism and genetic conditions were also presented to help healthcare providers strengthen their understanding of complex newborn conditions requiring early intervention.

Provincial and city health offices showcased local innovations that contributed to improved program implementation. Representatives from Sarangani, General Santos City, South Cotabato, Sultan Kudarat, and Cotabato Province shared strategies that enhanced screening coverage, improved monitoring systems, and reduced unsatisfactory specimen rates.

Outstanding healthcare facilities were also recognized during the workshops for achieving zero unsatisfactory newborn screening samples in 2025. Among the awardees were Rural Health Unit–Tantangan, Emelia Ancuna-Amante Birthing Home,

South Cotabato Provincial Hospital, Hinalaan Birthing Home in Kalamansig, Mlang Birthing Home, Tacurong Doctors' Hospital, Birhen sa Regla Medical Clinic and Hospital of Tulanun, and Community Health Services Cooperative Hospital of Midsayap.

Beyond recognition, the workshops resulted in concrete agreements aimed at strengthening newborn care implementation across the region in 2026. Healthcare facilities agreed to reinforce follow-up and reporting systems through the Newborn Screening Census Reporting System. Structured training requests for Expanded Newborn Screening, Essential Intrapartum and Newborn Care, and Newborn Hearing Screening were also clarified to ensure continued referral coordination, improve monitoring of performance indicators, and strengthen patient capacity-building among healthcare workers.

FHC-NCP DOH-CHD SOCCSKSARGEN



Participants of the Newborn Care Strategic Planning Workshop pose for a group photo, highlighting collaboration and commitment to improving newborn care services.

“Safe ba ang Anak Ko?” Webinar Highlights Importance of Early Detection for Rare Diseases

The UP Manila National Institutes of Health (NIH), in partnership with the UP Philippine General Hospital and the UP College of Medicine, conducted Webinar #275 titled “Rare Disease: Safe ba ang Anak Ko?”

The session featured Dr. Ebner Bon G. Maceda who discussed the importance of early diagnosis and management of rare diseases, such as Maple Syrup Urine Disease (MSUD), Pompe Disease, and Osteogenesis Imperfecta (OI).

Held on February 27, 2026, the webinar aimed to raise awareness about rare diseases, particularly those affecting children, and highlighted the crucial role of newborn screening in improving health outcomes and quality of life.

In the Philippines, rare disease is a condition affecting approximately 1 in 20,000 individuals. Many of these diseases are chronic, progressive, and genetic in nature, with around 75% affecting children.

Among the conditions discussed was Maple Syrup Urine Disease (MSUD), an inborn error of metabolism in which the body is unable to properly break down certain amino acids – leucine, isoleucine, and valine. The accumulation of these substances can become toxic and lead to serious complications if left untreated. Early symptoms may include poor feeding, irritability, and a characteristic sweet odor in the urine.

Although considered rare worldwide, MSUD is recognized as the most common inborn error of metabolism in the Philippines, with an estimated prevalence of 1 in every 71,932 births. Dr. Maceda emphasized that prompt diagnosis through newborn screening is essential to prevent irreversible complications. Management includes the use of specialized branched-chain amino acid (BCAA)-free formula and a carefully monitored low-protein diet.

The webinar also covered Pompe Disease, a rare lysosomal storage disorder caused by a genetic enzyme deficiency that affects the muscles, heart, and respiratory system. Another condition discussed was Osteogenesis Imperfecta (OI), commonly known as brittle bone disease, a genetic disorder characterized by fragile bones that fracture easily.

Throughout the session, Dr. Maceda stressed the life-saving impact of newborn screening. Detecting these conditions within the first few days of life allows timely intervention and treatment, significantly reducing the risk of

permanent disability and improving long-term outcomes for affected children.

The webinar formed part of the continuing public health education efforts of the UP Manila NIH and its partner institutions to strengthen awareness and advocacy for rare diseases and newborn screening in the Philippines.

The session may be accessed through TVUP on YouTube: <https://www.facebook.com/share/p/1DYV7N8fwb/>
VGMendoza





DOH-CALABARZON Strengthens NBS Programs Through Regional Alignment Meeting

The Department of Health’s Newborn Screening (NBS) and Newborn Hearing Screening (NBHS) Program strengthened its commitment to improving newborn health services in the CALABARZON region through a three-day alignment meeting held from February 18 to 20, 2026.

Gathering provincial and city coordinators from across the region, the activity served as a platform to align strategies, share latest program updates, and strengthen local implementation of newborn screening services. The meeting aimed to equip coordinators with updated technical knowledge, accurate coverage data, and enhanced operational competencies to ensure that every newborn has access to timely and quality screening services.

Health officials emphasized the critical role of newborn screening in preventing disability and reducing infant mortality through early detection and intervention. By reinforcing the capabilities of local implementers, the Department of Health seeks to improve the accessibility and efficiency of newborn services throughout CALABARZON.

During the sessions, Dr. Monica Stephanie Moreno and Dr. Mark Nicholas Santos presented key updates and strategic directions for the Newborn Hearing Screening Program. Their discussions highlighted current performance targets, emerging priorities, and action areas designed to strengthen early detection and intervention efforts for hearing impairment among newborns.

The meeting also focused on policy development and systems strengthening through a specialized workshop facilitated by experts from the University of the Philippines Manila Department of Behavioral Sciences. Led by Dr. Calvin de los Reyes, Prof. Laured I. Hernandez, Dr. Reynaldo Imperial, and Prof. Marilyn Crisostomo, the workshop guided participants in crafting and refining local ordinances and policies that will support stronger implementation of NBS and NBHS programs in their respective provinces and cities.

A major outcome of the gathering was the development of a comprehensive three-year strategic framework for 2026 to 2028 under the theme, “Born Protected: CALABARZON’s

Blueprint for Universal Newborn Protection.”

The framework outlines a shared vision and coordinated roadmap aimed at ensuring that every child in the region is protected from birth through strengthened health systems, inclusive policies, responsive services, and empowered communities. It also establishes measurable targets and collaborative actions to improve newborn screening coverage and long-term program sustainability.

Grounded in the principles of equity, resilience, and accountability, the blueprint aligns regional priorities with national and global child protection standards. Officials said the initiative will foster stronger multi-sectoral collaboration and create sustainable, long-term impact toward achieving universal newborn protection across CALABARZON.

At the meeting’s end, participants reaffirmed their commitment to advancing newborn health programs and strengthening partnerships among local governments, health institutions, and communities.

DOH-CHD CALABARZON

Health officials and local coordinators discuss updates and open referrals during the DOH CALABARZON newborn screening alignment meeting



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 📌 Newborn Screening Region 4A - Calabarzon

Lighting the Way for Rare Disease Awareness in 2026



As the country joined the global observance of Rare Disease Day on February 28, the Rare Disease Week 2026 once again cast a spotlight on the often unseen struggles of Filipinos living with rare conditions. This focus brings attention to the urgent need for accessible healthcare, stronger support systems and greater public awareness for patients and families navigating life with rare diseases.

As part of this year's observance, the #LightUpForRare campaign lit up landmarks across the country in a symbolic display of solidarity and hope for the rare disease community. The participating institutions and landmarks included the DOH Office of the Secretary Building, Rizal Park Manila, Fort Santiago Intramuros, Quezon Memorial Circle, De La Salle University, National Museum of Fine Arts, Baguio City Hall, Plaza del Gobernador Oriental Mindoro, Cebu Provincial Capitol, Cebu Cordova Link Expressway, and Leyte Provincial Capitol.

The annual lighting initiative served not only as a visual tribute but also as a reminder of the continuing challenges experienced by many Filipinos living with rare diseases. Despite the passage of Republic Act No. 10747, or the Rare Diseases Act of the Philippines, many patients still struggle with delayed diagnosis, limited access to specialized treatment, high healthcare costs, and inadequate support systems.

Advocates continue to call for the full implementation of the law to ensure timely and equitable healthcare services for persons with rare diseases. They emphasized that patients deserve the same urgency, dignity, and protection afforded to other vulnerable sectors, including Persons with Disabilities.

Several organizations remain at the forefront of these efforts, helping bridge critical gaps in awareness, education, and patient support. Among them are the Philippine Society for Orphan Disorders (PSOD), the Institute of Human Genetics, the Newborn Screening Reference Center, and the Volunteer Youth Leaders for Health (VYLH). Through sustained advocacy campaigns, community engagement, and educational initiatives, these groups continue to empower patients and families while strengthening public understanding of rare diseases.

This year's observance also illustrated the importance of collaboration among government agencies, healthcare institutions, patient organizations, and communities in building a more inclusive and responsive healthcare system.

As the Rare Disease Week 2026 concluded, advocates and stakeholders reaffirmed their commitment to ensuring that no patient is left unseen or unheard. The continuing message of the movement remains clear: through stronger policies, greater public awareness, and sustained government action, the Philippines can move closer to a future where persons living with a rare disease receive the care, support, and recognition they deserve. **LABarcial**

DOH Convened 2026 National Rare Disease Forum

In support of the implementation of the Rare Disease Act of the Philippines (Republic Act No. 10747), the Department of Health (DOH), through the Disease Prevention and Control Bureau – Child Adolescent and Maternal Health Division (DPCB–CAMHD), convened the 2026 National Rare Disease Forum on February 23–24, 2026 at the Manila Prince Hotel.

The forum aimed to strengthen multi-sectoral collaboration, provide updates on national rare disease initiatives, and promote equitable and inclusive care for Persons Living with Rare Diseases (PLWRDs). It gathered representatives from government agencies, healthcare institutions, professional societies, patient support groups, civil society organizations, and academic institutions to advance coordinated action toward improving rare disease prevention, diagnosis, treatment, and long-term support in the country.

The activity came at a significant time for the global rare disease community. In February 2025, the World Health Organization Executive Board endorsed the proposed resolution, “Rare Diseases: A Global Health Priority for Equity and Inclusion,” with the Philippines serving as one of its co-sponsors. The resolution underscored the urgent need for comprehensive and equitable approaches to rare diseases, including timely diagnosis, access to treatment, and appropriate care systems for affected individuals and families.

Persons living with rare and undiagnosed conditions continued to face major challenges, including delayed diagnosis, limited access to treatment and support services, financial burden, social stigma, and exclusion. The forum sought to address these gaps by fostering collaboration among stakeholders and strengthening institutional capacity to respond to the complex needs of PLWRDs.

The event also highlighted the continuing implementation of the Integrated Rare Disease Management Program and the work of the National Rare Disease Technical Working Group (RDTWG), established under the Rare Disease Act. Composed of representatives from the DOH, UP Manila National Institutes of Health (UPM-NIH), PhilHealth, Food and Drug Administration, medical societies, and patient organizations, the RDTWG played a central role in aligning national efforts on rare disease management and access to orphan drugs and products.

Among the forum’s objectives were increasing awareness of rare diseases among healthcare professionals, promoting research initiatives, improving access to essential services, and developing more inclusive systems of care for individuals and families affected by rare diseases. The two-day program featured plenary discussions, patient advocacy presentations, breakout workshops, and the simultaneous convening of the National Rare Disease Technical Working Group Meeting. Topics included navigating the diagnostic odyssey, challenges in accessing orphan drugs and products, and optimizing supportive management for PLWRDs.

Key speakers included Dr. Carmencita Padilla, who discussed the journey of the Rare Disease Program in the Philippines, and Dr. Ebner Bon Maceda, who delivered a session on empowering healthcare professionals and advocates to better understand and support persons living with rare diseases, and Dr. Jacinto Blas V. Mantaring III, who talked about the Health Technology Assessment for Rare Diseases. Representatives from patient advocacy organizations such as the Philippine Society for Orphan Disorders, MSUD Parent Support Group, SMA Philippines, and The Hemophilia Philippines Community Foundation Inc. (HAPLOS) also shared their advocacies and experiences during the forum.

Through this national gathering, the DOH and its partners aimed to strengthen collaboration across sectors and build a more responsive, inclusive, and equitable healthcare system for Filipinos living with rare diseases.

VGMendoza



Attendees sign the pledge of commitment to people living with rare disease



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