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Dr. Carmencita Padilla moderates a discussion addressing the sustainability challenges faced by India, Indonesia, Mongolia, Pakistan, and Vietnam.

Newborn Screening Champions from the Asia Pacific Region Consolidates Activities and Commitments

"Every child deserves the best chance for a healthy future" was the theme of the inspiring story shared by Hon. Budi Gunadi Sadikin, minister of health of the Republic of Indonesia, during a welcome dinner on September 2, 2024, for the participants of the 7th Workshop on Consolidating Newborn Screening Efforts in the Asia Pacific Region.

The three-day workshop was held at the Dusit Princess Hotel in Kathmandu, Nepal and organized by the Newborn Screening Reference Center (NSRC) in partnership with the Asia Pacific Society for Human Genetics (APSHG). Since 2008, NSRC has been serving as the secretariat to the workshops that gather newborn screening champions from different countries in the Asia Pacific region.

This year, country representatives from Bangladesh, Cambodia, India, Indonesia, Laos, Mongolia, Myanmar, Nepal, Pakistan, Philippines, and Vietnam have expressed commitment to working with the government, non-government, and private organizations for the expansion and sustainability of the newborn screening program in their respective countries.

During the welcome night, workshop convenors, Dr. Carmencita Padilla [PH], and Dr. Bradford Therrell, Jr, [US] welcomed the attendees and facilitated the sessions. Inspirational messages and stories were shared by Minister Sadikin; Hon. Teodoro Herbosa, secretary of the Department of Health Philippines; Brian Chung, president of the APSHG; and Anshu Banerjee, director of the Department of Maternal, Newborn, Child, and Adolescent Health and Ageing at the World Health Organization (WHO).

Minister Sadikin recognized the critical role of regional collaboration to achieve equitable outcomes for all newborns. He believed that this workshop was essential to the collaborative effort to enhance infant health. He expressed hope that the workshop will strengthen collaboration and spark innovative solutions for the challenges faced by the countries in the region. ...Continued on page 2



from p1... Sec. Herbosa expressed his gratitude to the Philippines' neighbors in the Asia-Pacific for going above and beyond to share their experiences, development, knowledge, and skills to foster growth and advance newborn screening in the region. He stressed that the Philippines will continue collaborating with its neighbors to find new ways to screen newborns as part of its commitment to helping them and building partnerships for a healthy future.

Pres. Chung shared that their solidarity stands strong in support of newborn screening and all related training and education activities. He mentioned their continued commitment to integrating professional development and public education into all areas of human genetics, from birth defects to rare diseases and all other medical conditions that have genetic predispositions.

Director Banerjee acknowledged that the workshop underscored the critical importance of comprehensive newborn screening and safeguarding the health of the youngest and most vulnerable segment of the society. He stressed that this workshop was not only timely but essential as it is aligned with the recent advancements in global health policy, particularly the outcomes of the 77th World Health Assembly.

Participants for this year's workshop got the opportunity to provide updates on screening data along with their own program implementation experiences during the three-day session. Issues on implementation, sustainability, and expansion in their respective countries were also discussed. All participating countries presented and talked about potential solutions they had identified for handling laboratory, administrative, and other challenges (including policies) that the program implementers faced.

Common issues like involving the government, expanding the program, securing funds, and setting up systems were also covered. The participants received guidance and advice from Dr. Padilla and Dr. Therrell regarding potential strategies to enhance their action plans for the next three years. As part of the activity, the practices and experiences from the US and the Philippines were also shared for potential adoption by other countries.

Following the conclusion of the most recent workshop in Kathmandu, the eleven participating countries agreed to adopt the commitments made in the Kathmandu Declaration:

- Continue regionalization and cooperation among countries by sharing expertise, information, and other resources in the implementation of universal newborn bloodspot screening.
- Continue working towards legislation and/or policy development within the Ministry of Health.
- Continue developing population studies to determine the incidence of genetic disorders in the region.
- Identify creative funding mechanisms such as inclusion in maternal/newborn/child benefit packages, health/social insurance, or other sources.
- Develop strategies to involve more health facilities in the program.
- Strengthen collaboration within the region.
- Work towards the improvement of the system and operations
- Increase awareness through development of culturally sensitive advocacy materials, and dissemination through various channels
- Improve access to and utilization of electronic data management systems in support of newborn bloodspot screening, and
- Appropriate documentation of satisfactory progress in completing all of the above items.

VGMendoza

Fifth G6PD Confirmatory Center in Metro Manila and 32nd in PH opens



Facade of the Dr. Jose Fabella Memorial Hospital

In the Philippines, 1 in 63 newborns has glucose-6-phosphate dehydrogenase (G6PD) deficiency, the most common screened disorder in the Philippine NBS program.

Diagnosing G6PD is through confirmatory testing which is one of the components of the National Comprehensive Newborn Screening System. In collaboration with the National Institutes of Health – Newborn Screening Reference Center, the Department of Health (DOH) established G6PD Confirmatory Centers in strategic areas to make the G6PD confirmatory testing more accessible. There are currently thirty-two (32) such centers located throughout the country.

The latest to be set up is the one at the Dr. Jose Fabella Memorial Hospital (DJFMH) in the San Lazaro Compound, Tayuman Street, Sta. Cruz, City of Manila, Metro Manila. The facility is the 5th G6PD confirmatory center in the National Capital Region, with the others as follows:

Center	Address
1. Manila Central University- Filemon D. Tanchoco Medical Foundation, Inc.	Samson Road, EDSA, Caloocan City
2. Our Lady of Lourdes Hospital	46 P. Sanchez St., Sta Mesa Manila
3. The Medical City	Ortigas Avenue, Pasig City, Metro Manila
4. University of Perpetual Help Dalta Medical Center	Alabang Zapote Rd. Pamplona III, Las Pinas City

...Continued on page 4



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The Philippine Society of Pediatric Metabolism and Endocrinology (PSPME) teamed up with the Newborn Screening Continuity Clinics (NBSCCs) at the Bicol Regional Hospital and Medical Center (BRHMC) and Bicol Medical Center (BMC) to spearhead this year's Follow- up Clinic on September 11-12, 2024, in the cities of Legazpi and Naga.

The activity aimed to provide specialized consultations for newborn screening confirmed positive patients with endocrine disorders such as Congenital Hypothyroidism (CH) and Congenital Adrenal Hyperplasia (CAH). This has become a part of the continuous treatment and management of patients with such conditions endorsed to the NBSCCs to check if the children grow and develop normally.

On September 11, 2024, specialists Dr. Lorna A. Abad and Dr. Susana P. Campos, with support from Dr. Marive A. Flores-Declaro and nurse Mary Joy M. Rebueno from the BRHMC NBSCC, assessed 26 patients, comprising 24 with CH and 2 with CAH, at the Healthy Lifestyle Complex, DOH Bicol CHD compound in Legazpi City. It was followed by an evaluation of 31 patients with CH and 3 with CAH the next day, aided by Dr. Michelle R. Semaña

and nurse Honeychille R. Repane from the BMC NBSCC. Both activities ensured the provision of consultations, health education, necessary medications, and support for optimal growth.

The NBSCCs are ambulatory clinics based in a tertiary hospital that conduct comprehensive newborn screening and treatment. These clinics provide patients with access to long-term continuity care and treatment. The BRHMC and BMC serve as the primary clinics in the Bicol Region offering regular follow-up services. Additionally, two satellite clinics have been established in this region: Eastern Bicol Medical Center (EBMC) in Catanduanes and Bicol Region General Hospital and Geriatric Medical Center (BRGHGMC) in Cabusao, Camarines Sur.

This initiative is being carried out in collaboration with the Newborn Screening Reference Center (NSRC) and is coordinated by the Department of Health (DOH) Bicol Center for Health Development through the Family Health Cluster-Newborn Screening Program.

DOH-CHD Bicol

Empowering Future Pediatricians: ENBS Orientation Series at Central Luzon



The doctors and future doctors posing with the Unit Head of NSC-CL, Dr. Bernadette Halili-Mendoza, after their ENBS orientation and laboratory tour.

The Newborn Screening Center – Central Luzon (NSC-CL), in collaboration with its host institution, the Angeles University Foundation Medical Center (AUFMC) Department of Pediatrics, hosted a series of expanded newborn screening orientations and laboratory tours for the latter"s pediatric residents, post-graduate interns, and clinical clerks. The sessions were an integral part of the training process of doctors and future doctors, aimed at enhancing their understanding of the importance of newborn screening, basic protocols, and laboratory operations.

The most recent session was conducted on September 18, 2024, and was attended by 20 residents, post graduate interns, and clerks. Dr. Bernadette Halili-Mendoza, NSC-CL unit head, discussed basic facts about ENBS and the disorders included in the panel. Nikki Dela Cruz, NSC-CL program development officer, explained the different steps on how to implement the NBS program. Adelaida Mallari, NSC-CL quality assurance officer, led the laboratory tour and showed the participants how samples are processed, analyzed, and interpreted.

The primary goal of the orientations was to instill in the participants the significance of early detection, diagnosis, and management of heritable disorders. Gaining knowledge about newborn screening also enhances their ability to make informed decisions regarding patient care in the future. By understanding screening processes, they can better educate families about the importance of newborn screening.

NDDelaCruz





From page 2... The Dr. Jose Fabella Memorial Hospital is a 700-bed capacity, Level III (specialty and end-referral) teaching and training hospital for Obstetrics, Gynecology, Anesthesiology, Newborn Medicine, and Pediatrics. It is currently headed by its medical center chief, Dr. Salvador B. Evardone.

To guarantee the consistency and reliability of G6PD confirmatory test results, the DJFMH will take part in the International External Quality Assurance Program (EQAP) of the Preventive Medicine Foundation (PMF) in Taiwan in cooperation with the NSRC, with all DOH-licensed G6PD confirmatory testing centers in the country.

The G6PD deficiency is an x-linked inherited disorder in which upon a baby"s birth, there is already something wrong with how his or her body makes and breaks important substances. In this case, it lacks the G6PD enzyme which helps in the protection of red blood cells from damage. **VGMendoza**

ENBS Saved Babies Family Day Celebrates Hope and Dedication

"You are silent heroes dahil yung mga pinalalaki ninyo nabibigyan natin ng normal na buhay."

This was how Department of Health-Metro Manila Center for Health Development (DOH-MMCHD) Asst. Regional Director Dr. Karen Fernandez described the attending parents in the Expanded Newborn Screening Saved Babies: Family Day Celebration to honor their resilience and determination in raising their children to lead normal and healthy lives.

The heartfelt message was delivered during the event held on September 26, 2024 in conjunction with the National Family Week at the Casa Ibarra, Pasay City.

"Kayong mga magulang na nandito, mga magulang ng na-save na mga bata na ito, saludo po ako sa inyo. Saludo



The saved children, their families, nurses, and coordinators participate in a magical show by a performer during the ENBS Saved Babies Family Day at Casa Ibarra, Pasay City on Sept. 26, 2024.

ako dahil ang tatag ng kalooban n'yo. Hindi natin alam in the future, isa sa kanila, congressman, doktor, abogado, at lahat ng mga pangarap na binubuo nila ay hindi matutupad at maisasakatuparan kung hindi dahil sa inyong mga magulang," she declared as she highlighted the roles of the family in her opening remarks.

Selected children from Metro Manila who were saved through the expanded newborn screening program attended the event with their families. The special celebration aimed to check on the health status of the children, ensure their continued access to necessary care, and promote the importance of newborn screening and other family health-related programs. The event also served as a platform to encourage the active participation and support of key health partners, parents, and other stakeholders in advocating for newborn screening across the region.

The celebration also highlighted the crucial role of partnerships in promoting family health. Partners of this event included the Department of Social Welfare and Development, Newborn Screening Reference Center, Newborn Screening Center-National Institutes of Health, Newborn Screening Continuity Clinics, Center for Human Genetics Services, Pasay City Health Office, Save the Children Philippines, DKT Philippines, and the 17 local government units of Metro Manila. Their combined efforts have contributed to the success of the NBS Program which continues to save lives by identifying life-threatening metabolic disorders at the earliest possible stage.



The ENBS Saved Babies Family Day Celebration was more than just a health initiative. It was a meaningful recognition of families who have embraced the program and a testament to the essential collaborations that ensure its success. It reinforced the importance of early detection in securing a child's future, and advocating for a stronger and healthier future for all Filipino families. Through collective action, it is expected that more children will gain access to health services that will help pave the way for a brighter future.

DOH-CHD Metro Manila





Western Visayas Involves Nutritionist-Dietitians in Metabolic Case Management through IEM Training

Region VI is home to at least 874 confirmed NBS cases, 12.13% of which are metabolic cases with disorders ranging from amino acid, fatty acid oxidation, organic acid, urea cycle defects and carbohydrate metabolism disorders. The basic management of these disorders includes nutrition therapy to maintain bodily functions.

From July 31-August 2, 2024, the Department of Health Western Visayas- Center for Health Development (DOH WV-CHD) in collaboration with the Center for Human Genetics Services (CHGS)-Visayas conducted the "Training on Inborn Errors of Metabolism for Long Term Follow-Up Clinics and Selected Tertiary Hospitals in WV" at the Punta Villa Resort, Arevalo, Iloilo City.

The three-day training aimed to capacitate healthcare workers in the clinical management of IEM cases. Likewise, it sought to improve the referral and management network to ensure that good quality of care is provided to children with special needs.

The lecture-discussions, action planning, and computation workshops during the training were spearheaded and facilitated by CHGS health personnel Dr. Barbra Charina Cavan- Geneticist, Jane Delfin-RN, Lawrence Sentillas-ND, and Maxine De Guzman-ND and NBSCC's Dr. Kristin Grace Guerrero-Gonzalez-Geneticist, Dr. Suzanne Marie Carmona-Barrera-Geneticist, and Diana Pondevida-RN. Doctors, nurses, and nutritionist-dietitians from the provincial and city health offices, NBSCC, Provincial NBS Satellite Clinics, and selected tertiary hospitals in the Western Visayas participated in the said activity.

To establish a sustainable long-term follow-up and management system for Inborn Errors of Metabolism (IEMs) patients in the region, close collaboration with the medical and allied health disciplines is essential. Referral points for more comprehensive and holistic care are identified with the NBSCCs and NBS satellite clinics as the central facilities that will link these referral points and cater to the needs of the metabolic patients.

FMODeaño

Joint Follow-Up Clinic Consultation: Enhancing Care for Positive-Screened Newborns

Joint Follow-Up Clinic Consultations by the Newborn Screening Continuity Clinics (NBSCCs) and the Philippine Society of Pediatric Metabolism (PSPME) and Endocrinology were held on August 23-24, 2024, and August 16-17, 2024 at the Dr. Paulino J. Garcia Memorial Research and Medical Center and Bulacan Medical Center, respectively.

The event brought together positive-screened newborns and long-term patients diagnosed with Congenital Adrenal Hyperplasia (CAH) and Congenital Hypothyroidism (CH), accompanied by their parents and guardians. Participants included representatives from various Newborn Screening Continuity Clinics (Jose B. Lingad Memorial General Hospital, Dr. Paulino J. Garcia Memorial Research and Medical Center, and Bulacan Medical Center). Additionally, members of the PSPME, Philippine Society for Developmental



Patients, their families, and their healthcare providers gather for a photo during the Joint Follow-Up Clinic Consultations by NBSCCs and PSPME.

and Behavioral Pediatrics (PSDBP), and representatives from the Central Luzon Center for Health Development were also present.

The primary goal of the activity was to enhance care coordination among NBSCCs and patients, ultimately improving outcomes for those with inborn errors of metabolism. This initiative aimed to promote full compliance with one-on-one consultations, allowing for personalized care plans that cater to each child's specific needs. This joint clinic consultation represents a significant step in enhancing care coordination for positive-screened newborns, fostering collaboration among healthcare providers and families. It aimed to strengthen the effectiveness of newborn screening initiatives and the long-term care management of positive-screened newborns in Central Luzon.

Resource persons were Dr. Lalaine Audrey M. Untalan, Dr. Angela Marie De Leon-Leyco, and Dr. Sharon B. Gawigawen from PSPME and Dr. Leanith D. Agustin of PSDBP.

JLCanlas





Enhancing Knowledge on Nutritional Management of Newborns with IEM

An orientation on the Nutritional Management of Screened Newborns with Inborn Errors of Metabolism, and a Supply Management Workshop for follow-up nurses were held on August 19-22, 2024 at the Widus Hotel, Clark Freeport Zone, Pampanga.

The event was attended by physicians, nurses, midwives, and nutritionist-dietitians from selected government and private healthcare facilities and provincial and city NBS coordinators. Representatives from the Newborn Screening Reference Center (NSRC), Center for Human Genetics Services (CHGS), Newborn Screening Center Central Luzon (NSCCL), Newborn Screening Continuity Clinics (NBSCC), Central Luzon Center for Health Development, also attended the event.

To boost awareness and competency among healthcare professionals in Region 3, specifically nutritionist-dietitians and NBS coordinators from various public and private health facilities, the workshop focused on enhancing their knowledge and skills on the nutritional management of inborn errors of metabolism (IEM) in screened newborns.

The initiative aimed to improve newborn screening services and ensure better health outcomes in Central Luzon. The workshop concluded with hands-on computation sessions led by the CHGS team, aimed at enhancing skills in the nutritional management of prevalent IEMs, including Phenylketonuria (PKU), Maple Syrup Urine Disease (MSUD), Glutaric Aciduria Type 1 (GA1), and

Physicians, Nurses, Midwives and Nutritionist-Dietitians of Selected Government and Private Healthcare Facilities, Provincial and City NBS

Coordinators, NSRC, CHGS, NSC Central Luzon, NBSCCs, DOH-CHD Central Luzon, and Other Health Personnel at the workshop.



Fatty Acid Oxidation Disorders (FAOD). Participants collaborated in groups, fostering a multidisciplinary approach to care.

In addition, workshops on supply management of expanded newborn screening medicines, medical foods, and orphan products gathered follow-up nurses from the NSCCL and NBSCCs. The primary aim was to equip participants with essential skills for effectively managing supplies that impact the efficient flow of goods, inventory, distribution, and utilization. Through educational sessions, attendees learned the best practices for annual forecasting and procurement of NBS-related goods, ensuring timely access for patients.

The workshop also included a comprehensive overview of a database utilized in Region 3, designed to support follow-up nurses in their roles. Overall, the events enhanced the participants' understanding of supply management principles, promoting better patient care and resource allocation.

Resource persons were Dr. Christine Mae S. Avila, Dr. Mary Erika V. Orteza, Jeanne Ruth U. Basas, Catherine Kaye B. Erestain, Roxanne Janica E. Merencilla, Kevina Mariz M. Dajoyaq, and Paulynne Marie M. Santos, all affiliated with the CHGS. JLCanlas

DOH-CHD CAR Holds ENBS Orientation for Chief Nurses



Dr. Virginia Narciso, DOH-CHD CAR LHSD Chief, emphasizes the importance of NBS in her welcome remarks

To further enhance neonatal care in the hospitals across the Cordillera Administrative Region (CAR), the DOH-CHD CAR NBS team conducted an orientation and update on the newborn screening program for chief nurses in Levels 1, 2, and 3 government and private hospitals in the region on August 15-16, 2024, at The Orchard Hotel in Baguio City.

This initiative headed by Dr. Virginia L. Narciso, DOH-CHD CAR Local Health Support division chief, is crucial for improving health outcomes for newborns and ensuring early detection of potential health issues by providing program knowledge and updates to the chief nurses of the hospitals. It emphasized their roles in implementing Republic Act 9288, otherwise known as the "Newborn Screening Act of 2004", in their health facilities. ... Cont p.7



Northern Luzon Conducts 8th Consultative Meeting

The Newborn Screening Center – Northern Luzon (NSC-NL) and the Department of Health – Center for Health Development (DOH CHD) Ilocos co-hosted the 8th Northern Luzon Consultative Meeting in Alaminos City, Pangasinan, on August 22-23, 2024. The annual meeting aimed to provide updates, address challenges, and ensure compliance with newborn screening standards for primary implementers. For this year, it sought to strengthen collaborations and identify improvements through a policy-making workshop.

Attendees included provincial health officers, newborn screening coordinators, program development officers, continuity clinic follow-up nurses, and G6PD confirmatory center representatives from Regions I and II. Dr. Ma. Lourdes K. Otayza, Medical Center Chief of Mariano Marcos Memorial Hospital and Medical Center (MMMHMMC) which hosts the NSC-NL, graced the event . Notably, DOH retained hospitals from the two regions participated for the first time.

The first day began with opening remarks by Dr. Rheuel C. Bobis, Head of the Disease Prevention and Control Section of DOH Ilocos CHD. NSCNL's Anthony James Almazan presented the meeting's rationale. Leslie Ann B. Malihan of NSCNL shared a review of last year's consultative minutes of the meeting, and Jovy Ann Lising from the Newborn Screening Reference Center (NSRC), National Institutes of Health UP Manila presented the national program updates and future directions. Reports

were then presented by NSC-NL, DOH CHDs, NBS Continuity Clinics, and G6PD confirmatory centers. Topics included success indicators, milestones, follow-up quality indicators, prevalence of disorders, and challenges. (insert name of agency) John Kristoffer B. Sacro reviewed the Regional Communication Plan, while Mr. Almazan discussed the Regional Contingency Plan and NBS Policy Workshop. Region 2 Regional NBS Coordinator Novelyn Lacuanan delivered the synthesis of Day 1.

On the second day, Vina G. Mendoza from NSRC led a discussion on existing NBS policies and facilitated the group activity on identifying issues and stakeholders. Karen Lois Dela Cruz and Anna Kharen Guillermo from PHO Pangasinan and Isabela, respectively shared their experiences in crafting ordinances in their respective provinces for an improved program implementation. Dr. Jessa Mae R. De Guzman, medical specialist from the Public Health Unit of the MMMHMMC, brought her expertise in policy development to the team and discussed drafting a blueprint for a provincial ordinance.

Participants then drafted ordinances based on assigned issues and concerns i.e. training and advocacy. Drafts were presented, evaluated by panelists and awarded. Dr. Ma. Lourdes K. Otayza delivered an inspirational message and emphasized the importance of compassion to push through significant initiatives and causes for the program. **LABMalihan**

from p.6... The activity highlighted the importance of early detection of heritable conditions for early diagnosis and timely interventions. Also emphasized was the weight of prompt recall and follow-up in significantly improving the quality of life and survival rates for affected infants.

The performance of the participating hospitals was presented by Nikki D. Dela Cruz, Newborn Screening Center-Central Luzon program development officer. Pertinent concerns were raised and strategies to address gaps were discussed during the activity. It was emphasized that there should be a dedicated health professional trained by the DOH-CHD to conduct quality NBS sample collection, transport of samples, and recall in each facility for an effective and efficient implementation of the NBS policy of these facilities.

The activity marked a proactive step towards improving neonatal

health outcomes by addressing challenges collaboratively in implementing the NBS policy in these health facilities, emphasizing education and capable human resource allocation, and availability of program logistics to ensure safe, accessible, quality, and affordable services among community members.





Chief nurses from private and government hospitals in CAR together with the DOH-CHD CAR NBS Team and NSC-CL







DOH Western Visayas CHD Mobilizes Youth Leaders for NBS Advocacy

The NBS partners and stakeholders in Western Visayas value the essential role of the youth in nation-building and promoting health and well-being because the YOUTH can!

With its persistent efforts in ensuring screening of all newborns for NBS disorders, the Department of Health Western Visayas Center for Health Development conducted a VYLH-Philippines Visayas Cluster Camp: Shaping the Next Generation of Health Champions last Sept. 27- 29, 2024 at the Nature's Village Resort, Talisay City, Negros Occidental.

Held in collaboration with the Newborn Screening Center Visayas and Volunteer Youth Leaders for Health-Philippines, the activity aimed to provide potential youth advocates with the necessary information to effectively disseminate and advocate the NBS program. Forty-four (44) youth leaders (15-30 years old) from various universities and community-based youth organizations from the different island groups of Panay-Guimaras, Negros Occidental, Negros Oriental, and Mindoro participated in the three-day activity and were given the batch name, Salinlahi.

As a commitment to the network, Batch Salinlahi discussed various school and community-based advocacy activities in support of campaign implementation during the regional planning session, including basic IEC campaign activities, advocacy lectures, etc.

The Volunteer Youth Leaders for Health-Philippines is a network of proactive, service-oriented, and empowered visionary leaders equipped with knowledge and skills to mobilize the youth toward addressing health issues. Currently, the network has four (4) advocacies: NBS program, folic acid supplementation, preconception health, and rare disease/orphan disorders. **FMODeaño**





G6PD Deficiency



Participants of the VYLH youth camp huddle together to prepare for the various activities of program.

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