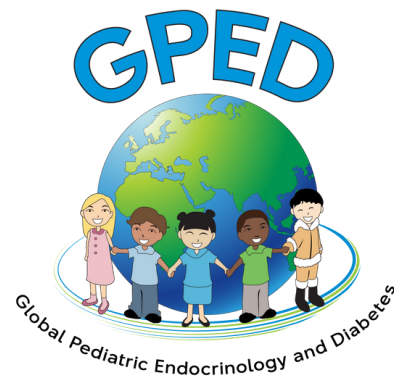


GPED Newsletter

Global Pediatric Endocrinology and Diabetes

Keeping you up to date on global health in pediatric endocrinology and diabetes around the world!

Issue 26 | March 2024



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Upcoming GPED Annual Meeting: August 2024!

We are extremely excited to announce our plans for the inaugural GPED Annual Meeting! Planning is currently underway with a format to include clinical updates, best practices for provision of care in resource limited settings, updates on international efforts and much more. This meeting will be virtual to allow for all our members to participate. In keeping with GPED's goal to provide education to all those providing endocrine care, no fee will be charged for this meeting. Registration details will be available on the GPED website in the coming months. We hope you can join us!

Introducing the New GPED!

Global Pediatric Endocrinology and Diabetes (GPED) has recently undergone a branding update to redefine who we are as an organization. As we work towards extending our reach to bringing endocrine and diabetes care to children globally, GPED has released our first official brand book. Learn more about who we are as an organization via the GPED website (www.globalpedendo.org) and access the brand book via the following link:

bit.ly/GPEDBrandBook

Upcoming Webinars

GPED Wishbone Day Webinar
Saturday, 4 May 2024 | 2PM GMT
Register [here](#)!

World Thyroid Day Webinar
Final week of May 2024
Stay tuned for more information!

GPED Webinar Series

One of GPED's programs focuses on education and research. GPED has recently relaunched the GPED webinar series surrounding various topics in pediatric endocrinology and diabetes, catered to local needs. Catch up on webinars recently conducted by GPED!

1. Tackling Common Problems in Congenital

Hypothyroidism Screening in Indonesia

Conducted on 3 September 2023, this webinar was conducted in collaboration with the Endocrinology Working Group of the Indonesian Pediatric Society, attracting over one thousand registrants from all over Indonesia. The Minister of Health of the Republic of Indonesia, Mr Budi Gunadi Sadikin, gave the keynote speech for the webinar and Professor Paul Hofman from the University of Auckland was the keynote speaker. During the interactive discussion, the panelists were joined by Dr Maria Endang Sumiwi, MPH (Director General of the MOH) and Dr Lovely Daisy (Director of Maternal and Child Health MOH). The webinar was conducted partially in Indonesian and in English. Watch the recording via the following [link](#).



2. Early menarche in adolescents:

Why to treat? When to treat? How to treat?

The “Early menarche in adolescents: Why to treat? When to treat? How to treat?” webinar was conducted in collaboration with the Endocrinology Working Group of the Indonesian Pediatric Society on 4 February 2024. Bringing two case presentations from Indonesia, an introduction from Professor Aman Pulungan and the keynote presentation by Professor Debra Millar (British Columbia Children’s Hospital), the webinar attracted over 400 live participants. The webinar was conducted in English. Watch the recording via the following [link](#).



We have a lot more webinars coming up, open for all GPED members to join. Stay tuned to GPED social media channels to keep yourself up to date!

New Article!

Global Pediatric Endocrinology and Diabetes collaborated with the Endocrinology Working Group of the Indonesian Pediatric Society to conduct a survey on the experiences and challenges of congenital hypothyroidism newborn screening in Indonesia. The results of the survey have been published in the International Journal of Neonatal Screening. Read the full article via the following [link](#).



International Journal of
Neonatal Screening



Article

Experiences and Challenges with Congenital Hypothyroidism Newborn Screening in Indonesia: A National Cross-Sectional Survey

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Abstract: The expansion of newborn screening (NBS) for congenital hypothyroidism (CH) is essential to reducing the number of preventable intellectual disabilities in children. Because of logistical issues, including geographic extremes, distinct cultures, and 4.8 million births annually, Indonesia has struggled to achieve universal NBS coverage. A national cross-sectional electronic survey was conducted to explore challenges in CH NBS. Responses from 423 healthcare professionals and program administrators across 30 provinces in Indonesia were collected. The major challenges reported were refusal from families (39.2%), newborns being discharged <24 h (38.3%), and limited availability of filter paper (35.9%). The respondents considered refusal from families to be due to fear, while others did not understand the necessity of CH NBS. The vast majority of respondents believed that parents do not have sufficient understanding regarding CH NBS (96.5%). Our study found that only 38.5% of respondents had received formal CH NBS training, with pediatric endocrinologists being the only profession in which all respondents had been trained. Concerted efforts are needed to improve the access to and availability of resources, increase the capacity for sample collection and analysis, empower healthcare professionals, and develop educational resources to promote understanding and acceptance of NBS amongst families.

Keywords: newborn screening; congenital hypothyroidism; experiences; challenges



Citation: Pulungan, A.B.; Puteri, H.A.; Faizi, M.; Hofman, P.L.; Utari, A.; Chanoine, J.-P. Experiences and Challenges with Congenital Hypothyroidism Newborn Screening in Indonesia: A National Cross-Sectional Survey. *Int. J. Neonatal Screen.* **2024**, *10*, 8. <https://doi.org/10.3390/ijns10010808>

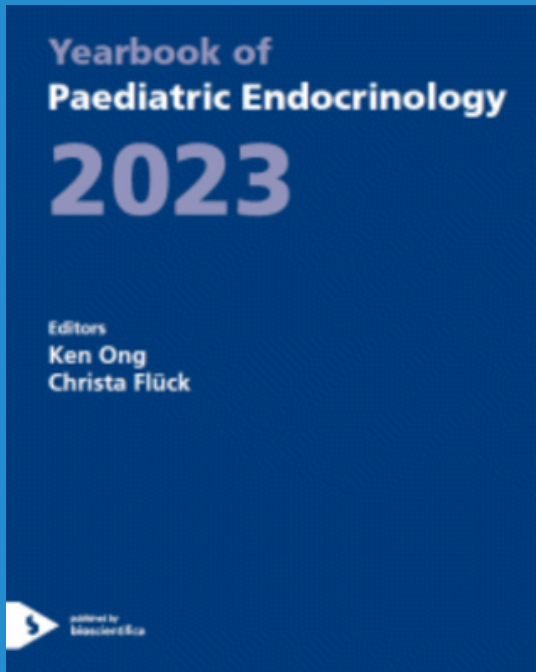
Academic Editors: Ernest M. Post and Ralph Fliegner

Received: 2 December 2023
Revised: 3 January 2024

Accepted: 8 January 2024
Published: 19 January 2024



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Yearbook of Paediatric Endocrinology 2023

Each year, the European Society for Paediatric Endocrinology (ESPE) publishes a Yearbook with expert commentaries on the most important articles published. Since 2016, the Yearbook of Paediatric Endocrinology includes a chapter on Global Health for the Paediatric Endocrinologist. The 2023 edition is no different!

The Global Health Chapter of the yearbook can be accessed by following the link below (if we can put the chapter itself as a link to the pdf on our website, all the better! The entire Yearbook 2023 is freely available via the following link.

This year's chapter includes 17 articles that cover not only the most significant articles on endocrinology and diabetes but also societal issues. Enjoy the read!

Fludrocortisone is now locally produced in Indonesia!

On 20 June 2023, the Indonesian Food and Drug Authority granted the distribution permit approval for Sydnacort, the first locally produced fludrocortisone tablet in Indonesia. By August, Sydnacort is now available in selected pharmacies and hospitals in Jakarta and major cities across the nation.

Like many other countries, congenital adrenal hyperplasia (CAH) patients in Indonesia have faced universal challenges for access to essential medicines. Before 2006, neither hydrocortisone nor fludrocortisone were registered for sale in Indonesia. For many years, CAH patients had to rely on donations. Collaborative efforts from organizations like CLAN, Indonesian pediatric endocrinologists and the CAH patient organizations (KAHAKI) enabled the CAH community to secure access for Hysone (hydrocortisone) tables and fludrocortisone tablets for a number of years.

Following the ten year journey of introducing locally produced hydrocortisone tablets (Genison) and injection (Fartison), the process of bringing Sydnacort to the CAH community began in 2017. The first formula was developed in 2018-2019, followed by a second formula development in 2019-2020. Upon pre-registration approval by the Indonesian Food and Drug Authority in 2020, a bioequivalence study was then conducted in 2021. After two long years of applying for the distribution permit, 2023 is the year CAH communities no longer have to rely on donations or the illegal marketplace to purchase fludrocortisone!

For CAH patients in Indonesia, coordinate with KAHAKI to inquire regarding pharmacies located close to you that provide Sydnacort.

Live 5-2-1-0

Live 5-2-1-0 is a simple, easy-to-remember message to help kids and families adopt healthy habits. The evidence-based message consists of four simple guidelines that children can work toward every day.



The Live 5-2-1-0 initiative partners with communities across BC to promote healthy behaviors among children. Together with Live 5-2-1-0 communities, we have created a range of useful resources and tools to help share and support the Live 5-2-1-0 message across all sectors of the community.

Our Live 5-2-1-0 'Fact sheet' and 'Early Years Fact Sheet' Resources have been translated into seven languages: Arabic, Korean, Vietnamese, Punjabi, Spanish, Chinese, and Filipino (Tagalog).

We've also created an 'Around the World Games Booklet' which is an inclusive compilation of over 20 popular games played by children in many countries and cultures around the world to encourage active play.

For more information about our initiative and access to over sixty free resource and tools, visit www.live5210.ca or contact us at info@live5210.ca.

Global Day of Action for #insulin4all: Insulin Equity Now!



Globally, one in two people cannot get insulin and testing supplies because it is unaffordable, inaccessible, or both. T1International's network is advocating globally for a world where the cost of insulin and glucose testing supplies represents no more than 5% of a person's income in any given country.

On March 16th, T1International is organising a Global Day of Action for #insulin4all. Advocates around the world will be delivering thousands of petition signatures to the Big Three insulin manufacturers: Eli Lilly in the United States, Novo Nordisk in Denmark, and Sanofi in France. And we will be holding solidarity actions around the globe to raise our voices in a united call for insulin access and affordability.

[RSVP to an Action Near You](#) and reach out to Shaina Kasper, Policy & Advocacy Director globaladvocacy@t1international.com for more information or to organize an action near you.

Global Pediatric Endocrinology and Diabetes

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