GPED Newsletter

Global Pediatric Endocrinology and Diabetes

Keeping you up to date on Global Health in Pediatric Endocrinology and Diabetes around the world

Welcome to GPED's 12th Newsletter!

Dr J von Oettingen

We are excited to announce our first ***globally*** edited newsletter! Huge thanks to out to colleagues from 5 different geographical regions around the globe who have joined our editorial board to bring more diverse perspectives, opinions and themes to this forum: Drs. **Francisca Grob** (Latin America), **Rasha Hamza** (Arab Countries), **Ganesh Jevalikar** (India), **Yun Yan** (China) and **Serwah Asafo** Agyei(Africa) - we are thrilled to have them as Associate Editors, and excited to showcase their first contributions in this newsletter!

In this edition, you will find updates about pediatric endocrine conferences by three of our member organizations: GPED @ESPE, SLEP and ASPED-ISPAD. NCD Child chair Dr. Marie Hauerslev is guest authoring a report on the Convention on the Rights of the Child and SDG #3, and two colleagues are providing perspectives on global newborn screening for congenital hypothyroidism.

Interested in contributing? We are looking for GPED members who are social-media savvy or simply interested in spreading GPED related news via our **Facebook** page at www.facebook.com/globalpedendo and/or via **Twitter** at twitter.com/GlobalPedsEndo.

Interested in contributing even MORE? Our secretary general Jean-Pierre Chanoine's term is coming to an end and we are looking for a GPED member who is interested in filling this exciting leadership position! Interested members please send an email to info@globalpedendo.org.

Enjoy the read!

Inside this issue:

GPED@ESPE in Vienna

Join us for an exciting symposium and round table on insulin access

Almost 100 years after its discovery, insulin remains out of reach for many children with Type 1 diabetes who live in LMICs. To understand why, what is being done and what YOU can do:

Join us for the GPED symposium during the ESPE meeting in Vienna on Friday September 20, 1400-1600 PM (Room TBD)

The Long Winding Road towards Sustainable Access to Affordable Insulin

1400-1405: Introduction: Dr Jean-Pierre Chanoine, MD, Pediatric Endocrinologist, Secretary General, GPED

1405-1435: Why Are We Failing to Address the Issue of Access to Insulin in Low- and Middle- Income Countries? A Global Perspective: **Dr David Beran**, MSc (Public Health), PhD, University of Geneva, Co-investigator of the ACCISS Study (Addressing the Challenges and Constraints of Insulin Access and Supply)

1435-1505: Insulin access: From the Model List of Essential Medicines to the Patient: New WHO Initiatives, **Dr Nicola Magrini,** MD, World Health Organisation (WHO) Expert Committee on the Selection and Use of Essential Medicines

1505-1535: Access to Insulin in China: Barriers and Opportunities, **Dr Xiaoping Luo,** MD, Pediatric Endocrinologist Chair, Department of Pediatrics, Tongji Hospital. Country: China

1535-1600: Round Table: How to Be a Leader on insulin access in your Country?

Pediatric endocrinology in Latin America: Connecting a continent through teaching

Dr F Grob

During December 2018, a Winter School organized by the education committee of the SLEP (Latin American Society for Pediatric Endocrinology) was held in Panamá. The goal was to strengthen the relationship between the SLEP and the scientific community of Central America and the Caribbean. For 3 days, 24 students from 9 different countries around the continent got together to improve their skills in the diagnosis and management of common pediatric endocrine diseases. Five international teachers from Chile, Argentina, Cuba, Guatemala and República Dominicana flew to Panama City to discuss growth, puberty and transgender medicine, among others, resulting in a highly valued activity for the attendees.

Additionally, and furthering the goal of bringing together pediatric endocrinologists in Latin America, **the 2019 annual meeting of the SLEP will take place in November in Florianópolis, Brazil**. Seven international speakers will be getting together to address the main topic of this meeting which is: "The present of the future: the impact of endocrine diseases and their treatments on the future life of pediatric patients." According to the president of the Congress, Dr. Sonir Antonini, an updated, innovative and interactive scientific program is being carefully organized that will contemplate the main topics of the specialty, from basic research to medical care.

Everyone is invited! https://slep2019.websiteseguro.com/espanhol/index.php

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Fifth ASPED-ISPAD Diabetes Academy: A Collaboration between Arab Society for Pediatric Endocrinology and Diabetes and International Society for Pediatric and Adolescent Diabetes

Dr R Hamza

The ASPED-ISPAD Diabetes Academy is an initiative by ASPED in collaboration with the ISPAD. It is an annual event sponsored by Lilly that aims at updating the knowledge of young physicians involved in the care of children and adolescents with diabetes in Arab countries. It also encourages sharing clinical experiences and collaboration in research projects between Arab countries. The academy adapts the format of an intensive course in basic and clinical science of acute and chronic disorders in Pediatric and adolescent diabetes and obesity. It also provides an opportunity for delegates to establish links and networking between each other and to interact with senior ASPED and ISPAD faculty members.

This year, the academy was held in the beautiful city of Muscat, Oman. Sixty seven participants from 20 countries (UAE, KSA, Egypt, Kuwait, Iraq, Sudan, Palestine, Oman, Qatar, Bahrain, Algeria, Tunisia, Morocco, Jordan, Lebanon, Luxemburg, Italy, UK, India and Pakistan) attended the course for 3 consecutive days. The curriculum was delivered via 20 plenary lectures, 2 plenary clinical case-based delegate presentations, a debate, 4 hands-on interactive workshops and small group discussions (case presentations and research projects presentations by delegates). Interestingly, the 4 best clinical cases or research projects from delegates were selected by the faculty to be presented in a plenary session.

The participants linked up with senior researchers, clinical experts, and fellow clinicians in a learning environment that encouraged active discussions and exchange of ideas. In addition, the social interaction between the faculty and delegates was remarkable. The feedback collected from delegates gave high marks to the organizing committee, the scientific value and the opportunity provided for networking and future collaboration.

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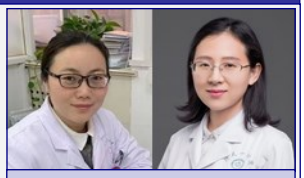
The progress of neonatal screening over the past 20 years in Henan province, China



Dr. Li, Xiaole Dr. Tian, Fengyan

Neonatal screening (NS) for inherited metabolic diseases and hormone disorders is very important since these conditions can result in severe morbidity (impaired physical or intellectual development) and mortality if they are not diagnosed early and treated appropriately. Some of the congenital diseases can be screened by rapid, simple and sensitive tests before the onset of clinical symptoms.

NS in China started in the early 1980s with pilot studies in Shanghai and Beijing. In 1994, the law of the People's Republic of China on maternal and infant health care was promulgated, which put forward for the first time the idea of "gradually carrying out the neonatal screening", thus providing a fundamental legal guarantee for the neonatal screening. From 1997 to 1999, the Neonatal Screening Cooperation Project between the governments of China and Finland was launched in five provincial and municipal screening centers, including Henan province. The project provided laboratory equipment for NS, offered professional and technical personnel training, established a NS network, and led to NS for congenital hypothyroidism (CH) and phenylketonuria (PKU). In 1997, the health department of Henan province established the Neonatal Screening Center, which serves as the provincial site responsible for the screening, treatment and follow-up of CH, PKU and congenital hearing impairment of newborns. From 2009-2018, NS in Henan province further developed and is now free for all.

Between 1997 and 2018, the annual number of newborns screened increased from 20,277 (=2.52%) in 1998 to 1.197 million (=96.49%) in 2018. More than 9 million newborn were screened. Between 2002 and 2011, we diagnosed 559 CH patients (incidence: 1/3118), 229 PKU patients (incidence: 1/7611). In 2012, the Neonatal Screening Center in Henan province took the lead role in carrying out mass spectrophotometry for neonatal screening and in expanding the number of screened diseases to 36, including lysosomal storage diseases (LSD), methylmalonate and severe combined immunodeficiency disease (SCID).

Since NS has been carried out in Henan province, 10,000 cases of physical and mental retardation, disability and death caused by genetic metabolic disease have been avoided, thereby reducing economic hardship on families and the community. Neonatal screening also has achieved significant psychosocial benefits, and play an important role in improving quality of life. With the continuous progress of technology, NS has a broad prospect and promising future in promoting the improvement of quality of life and safeguarding children's health. Henan province is a populous province in China. With the two-child policy being fully opened, the number of newborns in Henan province will keep increasing.

Edited by Yan Yun, MD, Pediatric endocrinologist, Children's Mercy Kansas City, Associate Professor, UMKC, USA
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Iodine supplementation with iodinated skin disinfectants: a reasonable last resource option?
SHARE YOUR EXPERIENCE

I was recently asked by one of my African colleagues whether GPED could provide iodine tablets for iodine supplementation in one of his patients.

As we all know, the best method to prevent and treat iodine deficiency and its most severe complications, endemic cretinism, is salt iodination of the population. If this is not yet achieved, iodine supplementation, using iodized oil PO or IM is the best alternative option, with a focus on vulnerable populations (children < 2 years, pregnant and breastfeeding mothers, women age 15-49). Various presentations of iodized oil are included in the WHO Model List of Essential Medicines.

However, if iodized oil is not available, could application of iodinated skin disinfectants on the skin be an option? It is not an approved indication but we have shown many years ago that the iodine contained in iodinated skin disinfectants crosses the unbroken skin very easily. Indeed, the application of povidone iodine for skin disinfection prior to a Cesarean Section causes iodine overload in the mother and the fetus. This question was also specifically addressed in a review article.

Although differences between iodinated skin disinfectants and individual variations in absorption prevent us from proposing a specific management plan, it is suggested that daily or weekly application of an iodinated skin disinfectant, usually readily available in most hospitals, could be a last resource option to manage iodine deficiency until population-wide salt iodination or administration of iodized oil is available. The dose could be adjusted based on clinical (size of the goiter) or biochemical (TSH) results.

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Ref: Iodine Global Network (www.ign.org/); Chanoine et al, Arch Dis Childhood 1988; Abraham, Original Internist 2008

The Convention on the Rights of the Child and Sustainable Development Goal 3 (SDG 3)

Dr Marie Hauerslev

On May 23, 2019, during the World Health Assembly (WHO, Geneva), NCD Child (www.ncdchild.org/) organised an event that illustrated the interconnection between the Convention on the Rights of the Child (CRC, https://www.ohchr.org/en/professionalinterest/pages/crc.aspx) and Sustainable Development Goal 3 (SDG, https://sustainabledevelopment.un.org/) (see newsletter 5, January 2017, https://www.globalpedendo.org/newsletter).

This year we celebrate the 30th anniversary of the CRC, a human rights treaty which sets out the civil, political, economic, social, health and cultural rights of children. The goal of SDG3 is to "Ensure healthy lives and promote well-being for all at all ages".

This event was co-organised by the American Academy of Pediatrics, NCD Alliance, and the International Pediatric Association and was sponsored by the Astra-Zeneca Young Health Program. Following a thoughtful introduction by George Msengi (Executive Committee Member, NCD Child) we heard stories by young leaders about the day-to-day difficulties of applying the CRC principles to the lives of those affected by NCDs. Margianta (Indonesia), Joab (Kenya) and Chantelle (South Africa) described how they fought, not always successfully, to defend their rights to a smoke free environment, to a life-saving kidney transplant and to improved mental health. We welcomed Dr. Stefan Peterson, UNICEF Chief of Health to lead a lively debate where the importance of the role of young leaders was emphasized in order to achieve SDG3 and the CRC.

Chantelle B

Joab W (L) and Stefan Peterson (R)

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NCD Child (Chair-elect) and Aarhus University Hospital, Children and Youth Psychiatry

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TSH Point-Of-Care testing and screening for Congenital Hypothyroidism: is it ready for prime time?

Dr JP Chanoine

More and more low- and middle-income countries are now starting to implement the systematic neonatal screening for congenital hypothyroidism (CH). However, CH screening, as it is presently performed in most high-income countries, requires a complex set up that includes collecting and shipping samples in a timely fashion to a reference, central laboratory. In countries where many deliveries take place at home or where shipping of the samples cannot be reliably performed over a few days, Point-Of-Care (POC) testing offers the potential to screen neonates at the bedside, obtain TSH results in a matter of minutes and initiate referral or management without delay.
Recently, The American Thyroid Association has published an update on the barriers and opportunities associated with POC testing (https://www.thyroid.org/wp-content/uploads/publications/lab-services/ata-poc-thyroid-management.pdf). This interesting document, which can be downloaded freely, describes the various assays that are presently available. It also cautions about potential limitations such as the interpretation of TSH whole blood results when the hematocrit is > 50 % (which is common in newborns) and emphasizes the importance of understanding the lower limit of detection of the TSH in a specific assay. Time will tell whether POC, which is presently expensive, can become a cost-effective approach in low income settings.

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Neonatal screening Program in Kerala, India

Baby steps are being taken in India for the implementation of newborn screening for congenital hypothyroidism (NBS). The Indian state of Kerala which has the best healthcare indicators amongst all states has taken a lead in this field. Following is a brief report of the NBS program by the Government of Kerala.

Dr M Vijayakumar

The Government of Kerala has initiated NBS in March 2013. Initially screening was started for 4 major childhood illnesses namely Congenital Hypothyroidism (CH), Congenital Adrenal Hyperplasia (CAH), Phenylketonutria(PKU) and Glucose 6 phosphatase deficiency (G6PD). Since Phenylketonuria could not be detected in any of the blood samples after screening for four years, this disease was replaced by Galactosemia from June 2018 onwards. As on December 2018, 461,663 neonates were screened. Government hospitals conducting 100 or more deliveries per month, including government Medical Colleges, were included in the first phase.

CH was diagnosed in 237 cases (prevalence 1 in 1948), CAH in 20 cases (1 in 11542), and G6PD in 46 cases (1 in 10036) after performing confirmatory tests. One case of galactosemia could be diagnosed since its introduction in the screening program. Majority of cases were from 2 major institutions, Government Medical College Kozhikode and Government Medical College Trivandrum. The Government has now planned to extend the program to the whole state to include deliveries conducted in private sector as well.

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