

GPED Newsletter

Global Pediatric Endocrinology and Diabetes

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



Dr J von Oettingen

Welcome to our 11th quarterly Newsletter!

Happy New Year! While many of you may start to settle into 2019, the first GPED newsletter of the year is looking back at 2018, providing you with a broad range of global pediatric endocrinology highlights. We have summarized 2018's global pediatric endocrinology related publications in this year's European Society for Pediatric Endocrinology Yearbook, are reporting on Chile's 2018 global pediatric endocrinology education events, are showcasing important advocacy efforts

on congenital hyperinsulinism and global access to insulin, and highlighting new guidelines for newborn screening in India.

In other news, in an effort to broaden the perspective on global pediatric endocrine issues, we are excited to announce the expansion of the GPED newsletter editorial team to 5 (!) additional colleagues from across the globe, spanning from Latin America, the Middle East, China and India all the way to Africa. Contributions from you, our members & readers remain more than welcome—send us your notice of events, announcements, your Op-Ed or commentaries to info@globalpedendo.org.

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Newborn Screening for Congenital Hypothyroidism in India: Let's Start!

An estimated 24 million babies are born every year in India. So far, systematic newborn screening for congenital hypothyroidism (NBS CH) has not been routinely available on a national level but the Indian Society for Pediatric and Adolescent Endocrinology (ISPAE) wants this to change. In 2018, ISPAE published two landmark papers that define the process of NBS CH in India. The articles have been featured in the 2018 ESPE yearbook, available on the GPED website and at <http://www.espeyearbook.org/>. Screening recommendations are tailored to the specific needs of this vast country and are described in a powerpoint presentation (Dr G Jevalikar et al, <http://www.ispae.org.in/Thymod.php>) on the ISPAE website. Patient education slides for families that explain what CH is and how to administer L-thyroxine are also available (<http://www.ispae.org.in/Thyroid.php>).

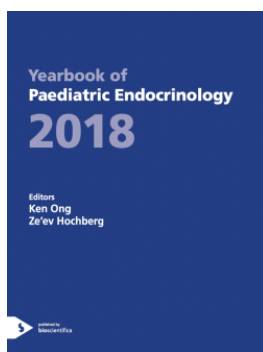
ISPAE (Dr P Dabadghao, President and Dr V Bhatia), the PES (Pediatric Endocrine Society, International Relations Committee (Drs S Raman and JP Chanoine) and GPED (Drs JP Chanoine and M Zacharin) are collaborating to ensure the success of the first phase of this ambitious project: raising awareness among the health professionals, the health authorities and the public about the importance of developing a NBS CH in India and educating them on the newly published ISPAE guidelines. GPED has secured an unrestricted grant from Novo Nordisk to help with this dissemination of knowledge.

The articles entitled "Clinical Practice Guidelines on Newborn Screening for Congenital Hypothyroidism", Parts I and Part II are available (for personal download only) FREE on Springer's platform till March 16th 2019. Please note that the pdfs are NOT to be forwarded in mass mails or put up on any website. To access the articles, follow the links below:

- Part I: Desai et al, Screening and Confirmation of Diagnosis
<https://link.springer.com/article/10.1007/s12098-017-2575-y>
 Part II: Sudhanshu et al, Imaging, Treatment and Follow-up
<https://link.springer.com/article/10.1007/s12098-017-2576-x>

For more information, please contact Dr V Bhatia, Department of Endocrinology, Sanjay Gandhi PGI, Lucknow
 Email: bhatiaviji@gmail.com

ESPE Yearbook 2018: Global Health Highlights



Since 2016, the traditional European Society for Pediatric Endocrinology **Yearbook of Pediatric Endocrinology** has included a chapter on **Global Health for the Pediatric Endocrinologist**. The 2018 edition is no different! For the first time, the yearbook is exclusively available online at <http://www.espeyearbook.org>, while the global health chapter can be found at <http://www.espeyearbook.org/ey/0015/ey0015.13.htm>. The 2018 global health chapter includes commentaries on papers relevant to global pediatric endocrinology published in the past year, with topics ranging from access to essential medicines and pathology and laboratory services in low- and middle-income countries, type 2 diabetes risk in global populations, pediatric diabetes in non-Caucasian youth, newborn screening for congenital hypothyroidism in China, India and Pakistan, and aspects of childhood growth pertaining to low- and middle-income countries. **Enjoy the read!**

Participate to the "International Registry" initiated by Congenital Hyperinsulinism International (CHI)



Julie Raskin

Today, Congenital Hyperinsulinism International (CHI) is very excited to announce the HI (congenital hyperinsulinism) Registry has launched. You can learn more about the HI Global Registry here: <https://congenitalhi.org/higlobalregistry/> and members of the patient community and their parents can join here: <https://www.higlobalregistry.org/>.

You can also learn more about the HI Global Registry in today's launch press release at this link: https://congenitalhi.org/wp-content/uploads/2018/10/HIGR_PressRelease_v1_10-08-2018.pdf

Please contact us for HI Global Registry brochures, fact sheets and postcards for patients and their families. We are happy to send you some to you in the mail.

Collaborating with global partners, CHI has launched the HI Global Registry to improve the understanding of congenital hyperinsulinism (HI), with the goal of advancing better treatments and the development of cures. The HI Global Registry will support clinical trials and foster other research studies in the field of HI.

The platform for the HI Global Registry was developed by the National Organization for Rare Disorders (NORD) with patient, family and advocacy input. Several other rare disease communities house their global registries on this platform. The HI Global Registry is a patient friendly online database that securely collects, stores and shares HI data. Participants of the HI Global Registry not only can share their experiences to advance research by filling in patient questionnaires, but they can also learn about other participants' experiences by viewing aggregated de-identified data reports in graphic form. This important initiative provides a powerful opportunity for the HI Patient Community to contribute directly to research, which will advance our understanding of HI, support the development of new treatments and improve patient care.

At the heart of the HI Global Registry initiative is the fundamental notion that collaboration with all research sectors (including healthcare professions, researchers, and industry) is essential to its success. The HI Global Registry provides the opportunity for both the HI Patient Community and interested collaborators to view the data and learn from it. As partners, we can all work together to foster patient engagement and retention for the collection and sharing of quality data that will advance HI research.

The Congenital Hyperinsulinism International HI Global Registry Research Team would very much appreciate your interest and support with the HI Global Registry. The HI Global Registry website is www.congenitalhi.org/higlobalregistry/. We hope you will share it with your patients and other potential interested parties.

In the meantime, if you have any questions, please reach out to us by email at info@higlobalregistry.org or call us 973-842-7559.

Julie Raskin, Executive Director, Congenital Hyperinsulinism International
Email: jraskin@congenitalHi.org

#Insulin4All - the global crisis on insulin access



Frederick Banting & Charles Best

In 1921, almost 100 years ago, the discovery of insulin by Banting, McLeod, Best and Phillips lifted the death sentence off of type 1 diabetes (T1D). It became a treatable chronic condition for those with access to insulin. Aware of the impact, the scientists gave away any proprietary rights so that insulin could be made available to all who needed it. Fast forward to 2018, the most common cause of death for children with T1D remains lack of access to insulin.

Why? One of the barriers to insulin access is its lack of affordability. Half of the 100 million patients that need insulin globally cannot reliably afford their insulin¹. An “insulin oligopoly” by the three major pharmaceutical companies Sanofi, Novo Nordisk and Eli Lilly that control 96% of the global insulin market² impedes

development of competition and has led to soaring insulin prices over the past two decades. The problem is worse in low- and middle-income countries where many patients pay for health care out of pocket. In Haiti, for example, where 60% of the population live below the poverty line (USD \$2.41 per day), a USD \$20 vial is cost-prohibitive for the vast majority of patients. But even in high-income countries like the United States price surges from ~US\$25 per vial of rapid acting insulin in 2001 to over US\$250 in 2018 have challenged insulin access for an increasing number of patients. As a result, patients have started to turn to the black market, social media and crowdfunding sources to obtain their life-saving medication. Rationing of insulin, with sometimes fatal consequences, has more recently attracted the media’s attention and has fueled patient advocacy and lobbying efforts³.

While the issue is not new, it has gotten renewed attention internationally as awareness about non-communicable diseases is increasing on a global level, and as diabetes rates are skyrocketing in both high- and low-income countries. Patients and professionals have been raising their voices, from advocacy efforts such as the Insulin4All campaign by t1international (www.t1international.com) to lobbying campaigns by professional associations, and scientific publications⁴.

The “Addressing the Challenge and Constraints of Insulin Sources and Supply

(ACCISS) Study”, launched in 2015, has gathered valuable evidence documenting the barriers to equitable access to insulin in low- and middle-income countries⁵. Their most recent study on insulin production cost and potential prices for manufacturers estimates that biosimilar Regular and NPH insulins could cost less than US\$72 and insulin analogues less than US\$133 per year. In the midst of the insulin access crisis, there may be reason for careful optimism that wider global access to insulin *could be* possible. A global effort is needed to reduce regulatory barriers for biosimilar insulins, increase the number of competitors on the market, and facilitate public health system supported diabetes programs.



Pre/Post photo of the first patient



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Dr Julia von Oettingen

Pediatric Endocrinologist, Montreal Children's Hospital

Email: julia.vonoettingen@mcgill.ca

Education in pediatric endocrinology and diabetes of staff in low and middle income Latin American countries



Dr Francisca Grob

Greetings from Chile!

This year, the division of pediatrics of the Pontificia Universidad Católica de Chile organized the Basic Graduate course in endocrinology, thanks to a generous unrestricted grant from Pfizer Pharmaceuticals. The objective of this meeting was to promote knowledge and skills of pediatricians and internists who care for patients with endocrine conditions in Latin America but are not formally trained in the field.

The students came from more than 15 different Latin American countries. Flights and accommodation were provided by the conference during their stay in Chile. Speakers included Professor Constantine Stratakis, from the United States, Professor Ana Claudia Latronico, from Brazil and many adult and pediatric endocrinologists from Chile.

During three days, attendees learned about current trends to optimize the study, diagnosis and treatment of endocrinological pathologies; through active learning methodologies such as interactive lectures, round tables and workshops for the analysis of clinical cases. The course focused on various topics: Hypophysis, puberty, adrenal, diabetes and obesity, thyroid, and bone metabolism.

Besides, during the course, students and teachers stayed together at the same hotel, and shared all meals, which permitted a closer interaction between all participants, and therefore, created a unique environment of confidence and friendship.

We are willing to repeat this event in the near future, as we received more than 150 applications!

Dr. Francisca Grob, Pediatric Endocrinologist, Organizing Committee
Universidad La Católica, Chile
Email: fgrob@med.puc.cl



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

Secretary General:

Jean-Pierre CHANOINE, MD, FRCPC
(Academic)
Clinical Professor and Head

#334-3381 Cambie Street
Vancouver, BC
V5Z 4R3
Canada
Tel: +1 604 875 2345, ext 5120
Email: info@globalpedendo.org

GPED website: www.globalpedendo.org

Executive Committee:

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