

GPED Newsletter

Global Pediatric Endocrinology and Diabetes

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



GPED membership now > 200



Dr JP Chanoine

GPED membership continues to increase and we **now have 219 GPED members!** At the same time, thanks to the efforts of Drs Julia von Oettingen (Canada) and Aman Pulungan (Indonesia), GPED has entered the era of media communications, and is active on **Facebook** and **Twitter** (see below). This will greatly facilitate exchange of information among GPED members.

Education and research are two of the channels used by GPED to improve clinical care of children with endocrine conditions and with diabetes living in resource-constrained settings. We offer more than

70 education booklets for families and for health professionals that are freely available on GPED's website in more than 10 different languages (see Newsletter #4).

In addition, in collaboration with Caring and Living as Neighbours (CLAN), GPED has initiated several lines of investigations that aim at understanding the factors preventing optimal **access to medicines in resource-limited settings**. Which medicines relevant to our specialty are included in the WHO and National model lists for essential medicines (EMLs)? To what degree are fludrocortisone, oral and injectable hydrocortisone (used for the management of Congenital Adrenal Hyperplasia) really available to the patient in low income countries? GPED has been contacting many of you to support these projects. I am thankful to the many colleagues who have replied to our survey. The results of these investigations will be highlighted in the coming newsletters as well as published in peer-reviewed journals. They will support GPED's work to improve medicine access to those who need them.

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GPED is now on Facebook and Twitter!



GPED is entering the multi-media era! We are now available on facebook (www.facebook.com/globalpedendo) and twitter ([@globalpedendo](https://twitter.com/globalpedendo)). We added these social media tools to allow our membership to stay current on issues pertaining to global pediatric endocrinology and diabetes topics, as well as broader global health issues. We're also hoping to offer additional ways for you, our members, and the global pediatric endocrinology community as a whole to connect, communicate, and interact. Finally, we will use our facebook page to post and promote relevant events such as conferences and meetings.

You are not (yet) seeing your upcoming event on our facebook page? Leave us a message on our facebook page or email us at info@globalpedendo.org so we can add it on and tweet it out!



Join us: Working Group on Global Health in Pediatric Endocrinology and Diabetes 10th International Meeting of Pediatric Endocrinology

The 10th International Meeting of Pediatric Endocrinology (www.internationalmeeting2017.org/) will take place in Washington, DC on September 14-17, 2017. **For the first time, there will be an abstract category entitled “Global Health”.** In addition, a working group meeting in Global Health in Pediatric Endocrinology and Diabetes, will take place on Thursday **September 14, 2017 (830-1130 AM)**, immediately prior to the opening of the meeting. I hope that you will be able to join us to discuss two important themes: Access to Medicines and Newborn Screening in resource-limited settings. I am delighted to share a **preliminary draft** of the working group meeting that will be updated through GPED’s Facebook page and Twitter account:

Theme 1: Access to medicines in Pediatric Endocrinology and Diabetes

Non-Communicable Diseases in Children and Adolescents and Access to Medicines

Jonathan D. Klein Executive Director, NCD Child, New York USA

Management of Congenital Adrenal Hyperplasia in Sudanese Children: Barriers and Opportunities

Mohamed Abdullah Khartoum, Sudan

Understanding access to medicines for the management of CAH in resources limited settings: preliminary data of a global survey

Jean-Pierre Chanoine Vancouver, Canada

Theme 2: Newborn screening in low income settings

Acceptance of Newborn Screening in Low Resource Settings

Carmencita Padilla U of Manila, Philippines

Eradicating Iodine Deficiency, a Prerequisite to Newborn Screening for Congenital Hypothyroidism

Elizabeth Pearce Boston USA

Discuss with us: Does “non-communicable diseases” merit a better name?

THE LANCET Global Health

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Luke N. Allen and Andrea B. Feigl launch a very relevant discussion to global pediatric endocrinology and diabetes issues in a comment entitled “**What’s in a name? A call to reframe non-communicable diseases**”, published in the most recent edition of The Lancet Global Health.

NCDs kill 38 million people each year and have surpassed their name-giving counterpart as the world’s number 1 killer. Disproportionately affecting persons living in low- and middle income countries (LMIC), there is an increasing and socioeconomically unequally distributed disease burden that is inadequately being responded to. The NCD name, a non-definition that may imply the notion of a non-

issue and of non-urgency, may in part contribute to the low level of global attention, political priority and funding currently being applied to this group of diseases—despite a clear demonstration that they represent the next most urgent epidemic. Further, there is robust data to support the communicability of NCDs, both in traditional ways (such as viruses transmitting cancer risk), but also less known routes such as transgenerationally (diabetes being one example), via social networks, the built environment, cultural traditions, and economic trajectories. Lastly, while the name NCD largely implies risk inference largely through individual factors such as predisposition and behavior, a name that recognizes the implication of societal and system-wide factors may prompt thought about population-based policies and interventions.

In an attempt to refocus the global response to NCDs, the authors suggest that a name change may help to reframe NCDs, raise awareness, and reinitiate a debate around actions required to tackle them. While there isn’t yet a concrete suggestion for a new name, the notion of “societal” and “ecological” are proposed as they may represent the types of ‘pathogens’ known to be tightly linked to NCDs: social injustice, globalisation, socioeconomic transitions, and poverty itself.

In thinking about our pediatric endocrine patients, this debate seems real, timely and essential. To name a few, consider the heritability and influence of our built environment on childhood obesity and type 2 diabetes, the socioeconomic factors affecting glycemic control in type 1 diabetes, and the lack of priority and attention given to global access to newborn screening for congenital hypothyroidism, or to essential medicines for endocrine diseases. The debate is open and readers are invited to join the discussion with *The Lancet Global Health* online. Let’s get our voices heard.

Support the rights of the child living with congenital adrenal hyperplasia



Dr K Armstrong

CLAN (Caring & Living as Neighbours - www.clanchildhealth.org - see Jan 2016 GPED Newsletter) is proud to officially launch their Child-Friendly CAH Rights Flyer on the UN World Day of Social Justice. The flyer has been developed as part of CLAN's official commitment to UN Secretary General Ban Ki Moon's Every Woman Every Child Movement and aims to raise awareness of the rights of every child living with CAH to achieve their full potential in life.

According to the UN Convention on the Rights of the Child (UNCRC), children living with CAH have the right "to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health". The UNCRC holds the entire international community responsible for "striv(ing) to ensure that no child is deprived of his or her right of access to such health care services".

The UN World Day of Social Justice (www.un.org/en/events/socialjusticeday) was selected as the launch date for the new CAH flyer, as it speaks to the many challenges faced by the international CAH Community. CAH is the most common adrenal condition of childhood and yet so many children around the world are still unable to access affordably hydrocortisone and fludrocortisone tablets. These two drugs were included in the World Health Organisation's Essential Medicines List for Children in 2008, and yet they are still not registered and affordably available to #EVERYchild living with CAH in every country.

To share the flyer with the CAH Community in YOUR country and to support the international launch on social media on **20 February 2017**, please email info@clanchildhealth.org for more information or follow us on Twitter @clanchildhealth and Facebook. We will be using #CAHCommunityLinks, #EVERYchild, #LeaveNoChildBehind and #Access2Medicines as hashtags. Together we can make a difference for children and adolescents living with CAH!

GPED is proud to support this initiative.

Kate Armstrong, CLAN President & Founder, Sydney, Australia; Email: kate@clanchildhealth.org
To access the flyer: www.clanchildhealth.org/Chronic-Conditions/Children-have-a-right-to-health

What do Children Living with CAH Need to Live a Happy and Healthy Life?



EVERY child living with CAH should have affordable access to hydrocortisone and fludrocortisone tablets and hydrocortisone injections. These drugs are on the WHO Essential Medicine List for Children.



All families should have access to information on CAH in their own language and to a trained health professional. Research on CAH is also important.



Children living with CAH must visit their doctor for regular check-ups. They also need access to emergency treatment on sick days.



The chance to connect with other people who are living with CAH for support and encouragement helps children and families learn and grow as a community.



Every child with CAH should enjoy a fulfilling life, free from social stigma and isolation. Every child with CAH should attend school and have the opportunity to play sports.



CAH can be easily diagnosed with heel-prick testing of newborn babies. The test is cheap, safe, accurate and saves lives by diagnosing CAH early.

Anthropometric calculator



Dr Dan Metzger

Dr. Metzger has recently released an Android-only app called "**Anthropometric Calculator**". The app calculates percentiles and Z-scores for height, weight, body-mass index, waist circumference, head circumference, height velocity and blood pressure for normal children (using WHO or CDC references), and some growth parameters for children with a number of syndromes (Turner, Down, Prader-Willi, Russell-Silver and Noonan). Citations are provided for each reference range used for the calculations.

Please email Dr. Metzger at dmetzger@cw.bc.ca if you have any questions about the app or suggestions about fixes or improvements. At present, there is no iOS version available. Desktop versions are available on the British Columbia Children's Hospital website, <http://www.bcchildrens.ca/health-professionals/clinical-resources/endocrinology-diabetes/tools-calculators>.

The "**Anthropometric Calculator**" app is available on Google Play.

Daniel L. Metzger, MD, Pediatric Endocrinologist, BC Children's Hospital, Clinical Professor of Pediatrics, University of British Columbia, Vancouver

In the news: Sustainable Development Goals (SDG) and Non-Communicable Diseases



Dr JP Chanoine

This new section of the newsletter is devoted to the discussion of important publications that are relevant to the practice of Pediatric Endocrinology in Low and Middle Income Countries (LMICs).

In September 2000, the Heads of State signed the United Nations Millennium Declaration, which contained 8 goals. Millennium Declaration Goal 4 (MDG 4) was to reduce the under-five (U5) mortality rate by two-thirds between 1990 and 2015. In 2015, the UN convened to prepare a post-2015 development agenda. It contains 17 very ambitious Sustainable Development Goals (SDG) that cover most aspects of sustainable living. Importantly, while MDGs did not focus specifically on NCDs, NCDs are

now a SDG target with the goal of decreasing by 1/3 mortality due to cardiovascular diseases (CVD), cancer, diabetes and chronic respiratory diseases (CRD) which account for 2/3 of NCD mortality.

Pediatric endocrine conditions and type 1 diabetes represent of course a very small part of the global NCD mortality. However, the Inclusion, for the first time, of NCDs in the SDGs is important for 2 reasons: first, it officially acknowledges the importance of NCDs in the overall strategy for better health and second, it specifically mentions type 2 diabetes (which is expected to be very prevalent in low income settings over the next 20 years) and its predisposing factors (excess body weight and insufficient physical inactivity, which have their roots in childhood and adolescence).

The target for NCDs is mostly discussed under SDG 3 (to “ensure healthy lives and promote wellbeing for all at all ages”). As capacity in pediatric endocrinology and diabetes is increasing, we are starting to understand the consequences of suboptimal management of pediatric endocrine conditions and diabetes in low income settings. It is suggested that pediatric endocrinologists should ride the SDG wave and participate to the global effort of betterment of health in children by advocating for better recognition, diagnosis and treatment of pediatric endocrine conditions and diabetes.

Reference: Boerma T et al. Health in 2015: from MDGs, Millennium Development Goals to SDGs, Sustainable Development Goals. Chapter 6: Noncommunicable diseases. 2015.



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