

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 25th Newsletter.
Help us develop the new GPED!**

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GPED was developed by the late Prof Zeev Hochberg more than 15 years ago. Zeev's excellent vision was to put together a group of pediatric endocrinologists from around the world and work collegially to support clinical care in children and adolescents with endocrine diseases living in low and middle income countries. GPED was later established in 2010 and incorporated in 2012 in British Columbia, Canada and became a Canadian charity soon after. Over the years, more than 400 colleagues have signed up to be part of this adventure.

Among many activities, GPED has been offering a newsletter 3-4 times a year since 2013. It has shared information from colleagues living in the 5 continents and has made resources available in various languages for health professionals and families alike. GPED has been active on social media. Several ongoing large projects have funded thanks to the leadership or co-leadership of several GPED members, including a training program for diabetes nurses in Sudan and a Master program in Pediatric Endocrinology in Francophone Africa. GPED fully supports the e-learning program and the telemedicus initiatives that offer novel opportunities for education and for clinical case discussions. A focus of GPED is access to medicines in low and middle income countries through donations but also through support of sustainable initiatives such as the recently developed CAH@MATES4Kids (see P 3) spearheaded by Caring and Living as Neighbours (CLAN), an Australian NGO.

None of this would have been possible without the wonderful support of ESPE. We feel it is time for GPED to go to the next level and be able to offer consistent initiatives to its members. Drs Diane Stafford (Stanford University School of Medicine, San Francisco, USA) and Jean-Pierre Chanoine (Vancouver, Canada). Go to Page 2 to see a glimpse of what GPED could and will be.

Join us at ESPE in The Hague on September 23 (1530-1700)

Future scientific meetings



The 61st ESPE 2023 Annual Meeting will take place September 21-23 in The Hague, Netherlands (<https://www.eurospe.org/event/61st-espe-meeting/>)



Pediatric diabetes in a rapidly changing world

The ISPAD 2023 Annual Meeting will take place October 18-21 in Rotterdam, Netherlands (<https://2023.ispad.org/>)



The PES 2024 Annual Meeting will take place May 2-5, 2024 in Chicago (<https://pedsendo.org/events/>)

If you wish to advertise future meetings, please contact GPED.

GPED: now and tomorrow. Join the Team!

Global Pediatric Endocrinology and Diabetes is (GPED) is a professional organization established in 2010. GPED aims at improving the care of children presented with endocrine disorders or with diabetes living in low and middle-income countries (LMICs) through public advocacy, education of health professionals, clinical collaborations and development of translational clinical research.

GPED is a member of the International Consortium in Pediatric Endocrinology (ICPE, <http://intpedendo.org/>). ICPE includes 13 regional professional societies. Except for ISPAD (and GPED). GPED is an NGO incorporated in Canada and a Charity. **We are looking for pediatric endocrinologists worldwide to help us build the new GPED!**

Executive committee

As a start, it is suggested that all committee chairs commit for 3 year-mandates, after which regular elections should take place. Quarterly zoom meetings are suggested. The Executive Committee will centralize the work of each Committee and provide feedback.

(Proposed) Committees and their roles

GPED aims at representing pediatric endocrinologists from each of the 6 WHO health regions (Americas, Eastern Mediterranean, South-East Asia, Western Pacific, Africa, Europe (<https://www.who.int/about/who-we-are/regional-offices>)). Each committee will be chaired by 2 members (preferably one from a LMIC and one from a HIC). Committee Chairs can designate Committee members. Regular zoom meetings are suggested, at the discretion of the Committee Chairs.

Finance committee

Funding is an important aspect of GPED and has been neglected. GPED membership has always been free. GPED funding was obtained through individual donations and through specific projects. There is presently no consistent funding stream. The concept of asking for a fee (for all or for those who wish to benefit from new activities) needs to be discussed. Categories of membership (full, paying, associate...) need to be considered.

Membership Committee

Members have been added as they registered and benefit from what GPED has to offer (Newsletter, translated booklets, contacts...). There is presently no process to review the membership on an annual basis. There is first a need to flush the list (contact and review who is still an interested member) and attract new members.

The Membership Committee can evaluate the type of membership, structure, process and so on. Full GPED members could be medical doctors with a majority of their practice in Pediatric Endocrinology and Diabetes. Associate Members maybe any health professional involved in the practice of Pediatric Endocrinology and Diabetes. Parents of patients may need to be considered.

Communications committee

GPED presently publishes a regular newsletter. Dr Aman Pulungan has been instrumental in getting GPED on Facebook, Twitter, Instagram and LinkedIn. The newsletter presently provides info concerning any relevant initiative in the world (global health in Ped Endo) while Facebook is easily accessible by all, potentially also parents.

The Communications Committee will review the existing website, ensure regular publication of the newsletter and regular update of the social media. Drs Aman Pulungan and Agustini Utari (Indonesia), Abed Abdu-Libdeh (Occupied Territory of Palestine and Israel) and Hannah Geddie (Canada) are presently serving on this committee.

Access to medicines and to diagnostic tests committee

Access to medicines is a major part of GPED's activities. One of the existing projects is the CAH@MATES4Kids project in collaboration with CLAN (HC and fludrocortisone). There are many other needs, ideas and opportunities. GPED's work with WHO as well as with the Lists of Essential Medicines (EML) and Essential Diagnostic Lists (EDL) is part of this commitment. Members of this committee will identify specific needs in countries and develop strategies and collaborations with their colleagues.

E-Learning and Education Committee

The e-learning program was originally developed by ESPE. Dr May Ng is a champion of this e-learning project. The e-learning program is already partially geared towards LMICs. It is generally underused (although it is changing fast!) and GPED should team up with ESPE and other regional societies to improve visibility and make it popular.

Specific education material/guidelines could be posted there as well. This would provide educational materials that are readily accessible from anywhere in the world. E-clinical case discussions can be discussed through Collegium Telemedicus. This was developed thanks to Dr Julia von Oettingen. It is up and running but is underused. This committee should also determine how to manage this program and how to increase utilization.

GPED is well positioned to provide expert recommendations (which will likely be more an expert consensus than an evidence-based work), particularly focused on provision of care in LMIC/resource limited settings. In 2013, Dr Margaret Zacharin has edited a book (Practical Pediatric Endocrinology in a Limited Resource Setting, available on Amazon as a printed and Kindle Edition. This unique book could help us Pediatric Endocrinology in a Limited Resource Setting, available on Amazon as a printed and Kindle Edition. This unique book could help us support clinical care in ways that are appropriate for local needs and resources.

We are looking forward to work with GPED members to reinvent GPED!

Jean-Pierre Chanoine and Diane Stafford

CAH@MATES4Kids: An update

In the December 2022 Newsletter, I reported on a Special Symposium organised with Dr Kate Armstrong (President of CLAN - Caring & Living as Neighbours - <https://www.clanchildhealth.org>) on Sat March 4, 2023, prior to the IMPE meeting.

The objective was to engage Pediatric Endocrinologists to be part of the CAH@MATES4Kids, **an international coalition of organisations and individuals committed to practical action to improve access to essential medicines and equipment for children living with CAH. It includes patient groups, health professionals and NGOs. CAH@MATES4Kids is aiming to reduce the preventable mortality associated with CAH by 30% by 2030** (this is aligned with the UN Sustainable Development Goals).

Pediatric endocrinologists play a vital role in the management of CAH in youth. to play in achieving the goals of this coalition. Kate and I have convened an international group of Pediatric Endocrinologists from across the six WHO Regions to actively support this initiative and network.

Following this successful symposium, under the leadership of Dr Paola Duran (Colombia), we have embarked on a journey that will map the needs for fludrocortisone and hydrocortisone around the world, identify regional manufacturers and clarify where neonatal screening programs are available. We hope you will be willing to be part of this group that will make a difference in improving affordable access to fludrocortisone and hydrocortisone in countries that need it. The ultimate goal is to actively support sustainable access in countries that need it. GPED is proud to be the pediatric endocrinology arm of the CAH@MATES4Kids.

Kate ARMSTRONG, BMed DCH MPH FAFPHM DrPH
President & Founder, CLAN (Caring & Living as Neighbours - www.clanchildhealth.org) Inc
Adjunct Associate Professor, Public Health, Torrens University

Medicines donations: the long road to sustainability. Bolivia and CAH

Dr Seoane is a pediatric endocrinologist in Santa Cruz, Bolivia. Unfortunately similar to many resource limited countries, neither hydrocortisone or fludrocortisone are available. This is even more frustrating once we realize that a neonatal screening for congenital adrenal hyperplasia (unfunded) is available in parts of the country, including in Santa Cruz where it was developed by Dr Seoane.

GPED, in collaboration with Health Partners International (HPI), has succeeded in providing Dr Seoane with 4000 tablets of hydrocortisone 10 mg in April 2023.

GPED is now working in close collaboration with Dr Seoane and with CAH@MATES4Kids (see above), to achieve sustainable access to both medicines.

Dra. Bany Seoane Justiniano, Pediatric Endocrinologist
Hospital de Niños Dr. Mario Ortiz Suárez, Santa Cruz, Bolivia
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Join us at the Science Summit at United Nations General Assembly (UNGA78) Wednesday 13th September, 6.00-8.30 PM New York time

Rodolfo Rey, CEDIE (Centro de Investigaciones Endocrinológicas), Buenos Aires, Argentina; Kate Armstrong, CLAN (Caring & Living As Neighbours), Sydney, Australia and Jean-Pierre Chanoine, GPED (Global Pediatric Endocrinology and Diabetes), Vancouver, Canada invite you to attend a session they organize during the United Nations General Assembly (<https://sciencesummitunga.com/>)

Innovative approaches in achieving sustainable access to healthcare for pediatric non-communicable diseases (NCDs) in resource limited environments.

Established in 2021, @MATES4Kids (Maximising Access To Essential Supplies) is an international movement of like-minded organisations committed to reducing the preventable mortality associated with childhood NCDs. With a focus on one particular chronic health condition (CAH - Congenital Adrenal Hyperplasia), the @MATES4Kids movement seeks to contribute in a practical way to efforts to achieve SDGs 3.2.1, 3.2.2 and 3.4 and to serve as a proof of concept for improving access to medicines for other NCDs.

Panelists will report on the activities of the @MATES4Kids Community of Practice to date. As an international movement (hosted on the World Health Organization's Knowledge Action Portal), @MATES4Kids is committed to collaborative action, leveraging existing technology and scaling innovation to #LeaveNoChildBehind.

@MATES4Kids proposes to reduce the preventable mortality associated with CAH and promote efforts to achieve the SDGs through three key objectives: Improve access to essential medicines (as per the WHO's Essential Medicines List for Children); Scale access to Newborn Screening and other diagnostics (as per the WHO's Essential Diagnostics List); Strengthen childhood NCD Communities

This session will review successful collaborative, rights-based, community development efforts by our group that have been shown to improve sustainable access to medicines and quality of life for children living with chronic NCDs in resource-limited environments. A panel of stakeholders will share key activities and achievements to date, as well as acknowledge barriers to the broader social, cultural and economic determinants of health for children living with NCDs in LMICs. Speakers will share updates on efforts across each of the WHO's six regions

Expected outcomes

Discussion of key learnings and successful approaches to date will inform the development of practical recommendations, tools and resources to help United Nations Member States scale action that will reduce the preventable and inequitable mortality currently experienced by infants and children living with chronic health conditions in resource poor settings, and thus contribute to SDG 3 "Ensure healthy lives and promote well-being for all at all ages" by 2030. Participants will be invited to join the @MATES4Kids Community of Practice on the WHO's Knowledge to Action Portal (<https://www.knowledge-action-portal.com/en/communities/overview>), access existing tools and resources, and engage in ongoing collaborative efforts to reduce preventable child mortality around the world.

Program

Introduction: Kate Armstrong, Jean-Pierre Chanoine and Rodolfo Rey

Successes and challenges in Southeast Asia: Jamal Raza

Successes and challenges in Middle-East countries: Aman Pulungan

Successes and challenges in Africa: Salwa Albuldagi

Access to hydrocortisone and fludrocortisone in Latin America: Paola Durán, Raúl Calzada

WHO EML and EDL: Jean-Pierre Chanoine

Training specialists for and in Sub-Saharan countries: Thomas Ngwiri

Towards a Toolkit for health professionals, communities, NGOs, health authorities and the private sector to work together: Kate Armstrong

Register for free at: <https://sciencesummitunga78.sched.com/event/104tY/virtual-innovative-approaches-in-achieving-sustainable-access-to-healthcare-for-pediatric-non-communicable-diseases-ncds-in-resource-limited-environments-131801>.

Medicines donations: the long road to sustainability. Kenya and OI



Kenya: Zoledronic Acid and Osteogenesis Imperfecta

In April 2022, GPED collaborated with the Center for International Health (CIH) at British Columbia Children's Hospital in Vancouver to facilitate the delivery of much needed zoledronic acid to children with Osteogenesis Imperfecta (OI) followed at Machakos Orthopaedic Clinic in Kenya (see Newsletter 23).

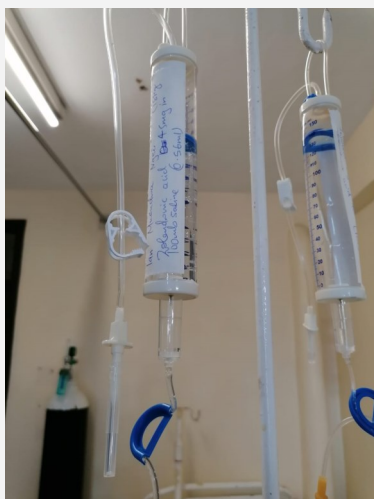
Dr Mbula Nguku wrote the following in November 2022:

"There are currently 32 patients in the program. Bisphosphonates like Pamidronate and now Zoledronic Acid have had a tremendous impact in their lives. The improvement in the quality of life in these patients its evident. A High School student who had dropped out due to pain and frequent fractures has

returned to school and will graduate from high school this year. He has not had a new fracture for the last 3 years. Primary school aged children who were unable to start school started in January 2023 because they are not having frequent fractures anymore. All schools in the home areas had refused to admit them to join school. Most significantly, there has been a significant reduction in pain in the patients. A small survey of 14 patients who received Zoledronic Acid showed that 11 of them mentioned they had no pain. The eldest patient, a 39 years old man who is currently wheelchair bound with significant scoliosis noted that for the first time in a very long time, he has been pain- free".

In March 2023, a second shipment arrived in Nairobi. Dr Mbula Nguku describes the most recent clinic:

"We gave the Zoledronic acid to the patients. Yesterday we started with 10. We had a full ward, the other patients are coming this week. It's such a blessing. One vial goes so far, it is not only for one patient: I actually managed to use one on several of them. They were admitted overnight and it was amazing that the fellowship they had together. They met other parents who have the same challenges. Conversations happened. One mum now wants to take her son to school. She had thought that the son couldn't join school. You have give these families hope".



In parallel, IDr Mbula Nguku is pursuing a lead in the local government hospital and am hopeful to get approval from the local government pharmacy at Machakos Level 5 and ensure sustainable access to zoledronic acid in patients with OI in Kenya in the future.

In the meanwhile, GPED is trying to support individual requests. Donations of medicines are often (but not always) available and the only cost is a modest administration cost to Health Partners International, a Canadian NGO that supports this initiative.

For more information, please contact:

Dr Speciosa Mbula Nguku

Anaesthesiologist/Pain Specialist

Acumen EA Fellow 2015; www.machakos-orthopaedics.org; Twitter: @machakosortho

The Life For A Child Extend 30 program: Extending support to age 30 for young adults in low-income countries



Life For A Child (LFAC, <https://lifeforachild.org>) is currently supporting over 46,000 young people with diabetes in 45 countries. LFAC activities include:

- Provision of essential supplies, including insulin, syringes, and blood-glucose monitoring equipment.
- Production of accessible education materials for children, families and healthcare workers
- Training to develop the skills of local medical professionals
- Research projects, which help to advocate for positive change.

Life For A Child has long been aware of the difficulties young people face when they reach the age of 26 and are no longer eligible for our support. Those in low-income countries are often the hardest hit, as there are fewer employment opportunities that provide enough income for diabetes supplies and care. Today, LFAC is pleased to announce that it will now support youth with diabetes until 30 years in low income countries. The countries that will Benefit from this extension are:

The LFAC countries that will benefit from this age extension include:

Burundi, Burkina Faso, Central African Republic, Democratic Republic of Congo, Eritrea, Ethiopia, Guinea-Bissau, Liberia, Madagascar, Mali, Rwanda, Sudan, Sierra Leone, Syrian Arab Republic, Togo and Uganda.

Emma Klatman, Global Policy and Advocacy Manager, Life for a Child

Email: emma@lifeforachild.org

For more information, please see:

- www.lifeforachild.org/about/extend30/
- <https://twitter.com/lifeforachild/status/1659167329488388098>
- <https://www.linkedin.com/feed/update/urn:li:activity:7064933707597398016>
- <https://www.facebook.com/photo?fbid=590212213213503&set=pb.100066741891722-2207520000>
- <https://www.instagram.com/p/CsYjBaJKcPG/>



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