Welcome to our 9th quarterly Newsletter!

2018 started out busy for many of us. However, as you will see in this edition of our newsletter we’ve continued to work on projects and ideas to improve diabetes and endocrine care for children around the globe.

As pediatric endocrinologists are graduating from new training centers in low- and middle income countries (see report on the Paediatric Endocrinology Training Center for Africa, PETCA, on page 4), more pediatric endocrinologists will practice in settings where access to insulin and other endocrine medications for children is not a given. Similarly, access to essential diagnostics for pediatric endocrine conditions is emerging as a major barrier to endocrine care in countries where colleagues are newly introducing pediatric endocrine care.

GPED has been advocating for increased availability of essential pediatric endocrine medications around the globe, including by applying for the addition of essential medicines to the WHO “Essential Medicines List”. But the work is far from being done, and more is up on the horizon: on May 15th WHO published its first ever “Essential Diagnostics List”, a list of 133 essential in vitro diagnostic tests (http://www.who.int/medical_devices/diagnostics/WHO_EDL_2018.pdf). While many essential tests made the list, including glucose and hemoglobin A1c, some endocrine tests deemed essential are clearly missing: Cortisol and TSH give way to a list of 55 “high-priority” diseases including HIV, malaria and TB. What should be on this list? Let’s discuss... at the GPED symposium during the 2018 ESPE meeting.
ADVOCACY CORNER: T1International

T1International — A report by Elizabeth Rowley

Life with diabetes is complicated.

Access to vital insulin, diabetes supplies and medical care should not be. T1International (www.t1international.com) is a non-profit run by people with type 1 diabetes for people with type 1 diabetes. We believe in a world where everyone with type 1 diabetes – no matter where they live – has everything they need to survive and achieve their dreams. We support local communities by giving them the tools they need to stand up for their rights so that access to insulin and diabetes supplies becomes a reality for all.

Our Type 1 Diabetes Access Charter campaign serves to raise public awareness and frame type 1 diabetes access issues as a human rights issue. Our advocates around the world use the Charter and the fact that it has so much global support as a way to bolster their advocacy. We encourage individuals and organizations to add their name in support of the five basic rights that all people with type 1 diabetes should have.

While we do not provide insulin and supplies, we work with communities to support their fight for long-term sustainable solutions to access issues. Our advocacy toolkit (https://www.t1international.com/toolkit/) is available in English, French and Spanish. It was created specifically for people with type 1 diabetes to do advocacy for the first time, or to strengthen any existing advocacy activities. Along with the toolkit, we provide online and occasional in-person training to help dedicated advocates focus on a goal, plan their action, and carry out a targeted project.

Currently, T1International is running a survey about out-of-pocket diabetes costs (www.t1international.com/survey2018). Patients, family members, and healthcare professionals can complete this survey to help build a global picture of diabetes costs and support advocacy for better access and policy change. Information and results from our 2016 survey can be found at www.t1international.com/insulin-and-supply-survey.

Elizabeth Rowley, Founder & Director, T1International
elizabeth@t1international.com
SWEET benchmarking for pediatric diabetes

SWEET!!! When was the last time your diabetes center looked at their diabetes outcomes? Compared your outcomes to others, and used that comparison to learn from others and improve care? SWEET could be the network to achieve exactly that.

Derived from “Better control in Pediatric and Adolescent diabeteS: Working to crEate CEnTers of Reference”, SWEET is a network for pediatric diabetes centers that aims at achieving “equal, high quality care for all children with diabetes” by “harmonizing care to optimize outcomes in children and adolescents with diabetes mellitus worldwide”. The network started in Europe in 2008, but since has recruited 80+ centers from 44 countries and is more recently increasing its efforts at going global!

Over the past years the International Society for Pediatric and Adolescent Diabetes (ISPAD) has supported the integration of diabetes clinic data in the SWEET database. This is becoming progressively a worldwide clinical registry. Such a registry will not only allow comparisons - benchmarking - between centers, but it can also contribute to combine forces in tackling diagnostic challenges, and in improving care for the rare forms of diabetes.

Join the ISPAD@SWEET Network!

ISPAD has started an initiative to have as many centers as possible begin collecting HbA1c and other data in a registry, and to take part in international benchmarking. ISPAD president Ragnar Hanas writes on the society’s website: “By comparing yourself with other centers, a very good discussion can arise within your local center, and you can begin pushing towards a lower HbA1c with whatever resources you have available.”

Currently, SWEET is seeing an increasing international representation from outside Europe—but is still lacking representation from Africa (only Mali currently has a participating center), Central and South America, and Asia. The most important requirement for SWEET membership is the documentation of data of your pediatric patients with diabetes at your center. Applications for membership can be found online: http://www.sweet-project.org/how-to-become-a-member.php, or by writing an email to sweet-project@hka.de. As part of an effort to recruit smaller centers (<150 patients), including from low- and middle-income countries, SWEET recently agreed to include 40 centers free of charge, in collaboration with ISPAD. Upon application, centers receive the SWEET software (called DPV) for data collection for free, and each year the center gets a report on how their unit compares with others in the SWEET register. The free-of-charge application is on a first come – first serve basis by contacting Ragnar Hanas at ragnar.hanas@vgregion.se. Centers with > 150 patients should approach SWEET directly for a regular membership, either as a Center of Reference or Collaborative Center.
ASPAE is thriving: first ASPAE summer school

The Paediatric Endocrinology Training Center for Africa (PETCA) is a comprehensive 18-month program that has led to a marked increase in capacity in pediatric endocrinology and diabetes in sub-Saharan Africa. The program accepts English-speaking pediatricians from Africa and consists of six months of training in Nairobi (Kenya) or Lagos (Nigeria), followed by nine months of practical experience in the candidate’s country of origin, and by a further three months in Nairobi or Lagos where trainees take examinations and submit a dissertation. The PETCA program has also led to the foundation in 2009 of the African Society for Paediatric and Adolescent Endocrinology (ASPAE, http://www.aspaed.org/), which aims at promoting “the highest levels of knowledge, research, education and clinical practice of paediatric endocrinology and metabolism throughout Africa”.

Dr Joyce Mbogo (Nairobi) organized the first ASPAE summer school. It took place on March 11-13, 2018, just prior to the 9th annual meeting of the ASPAE and was supported by the European Society for Paediatric Endocrinology (ESPE) and the International Society for Pediatric and Adolescent Diabetes (ISPAD). The program consisted in a mix of plenary lectures by former PETCA graduates as well as by international speakers and of clinical case presentations by PETCA graduates. It was attended by 28 very active participants!

Joyce Mbogo, Pediatric Endocrinologist MD FAAP, Nairobi, Kenya
Email: joyce.mbogo@outlook.com

Photographs courtesy of Martin Mulwa

Secretary General:
Jean-Pierre CHANOINE, MD, FRCPC (Academic)
Clinical Professor and Head
British Columbia Children’s Hospital
#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:
Jean-Pierre CHANOINE (PES)
Ze’ev HOCHBERG (ESPE)
Julia VON OETTINGEN (ISPAD)
Raul CALZADA (SLEP)
Iroro YARHERE (ASPAE)
Anju SETH (ISPAE)
Reiko HORIKAWA (JSPE)
Xiaoping LUO (CSPEM)
Suttipong WACHARASINDHU (APPES)
Asma DEEB (ASPED)
Jan LEBL (ESPE)
Elizabeth DAVIS (APEG)

© 2015 Global Pediatric Endocrinology and Diabetes.
The views expressed by the contributors are not necessarily those of GPED.