

19th newsletter | GPED



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Welcome to GPED's 19th Newsletter!

This edition of our newsletter brings innovative stories related to the of care of children with diabetes and endocrine conditions around the world. From diabetes camps in Kenya to the heat stability of insulin, efforts are underway to improve access to life saving medications and change the lives of children and their families living with endocrine conditions. Of course many challenges remain related to the COVID-19 pandemic, which is still wreaking havoc on many parts of the world. In addition to placing extreme stress on our medical systems, it is impossible to estimate the degree to which the pandemic has disrupted the delivery of ambulatory care. There is also growing concern regarding the impact of the virus itself on patients with endocrine conditions such as diabetes or adrenal insufficiency.

Despite the many challenges the world faces and the abundance of distressing information we find in the news, we hope that you will gain some much needed inspiration from the stories in this current issue. Enjoy!

'Our Rights to Health in Africa': A Type 1 Diabetes Youth Advocacy Workshop



Our Rights to Health in Africa: A Type 1 Diabetes Youth Advocacy Workshop On June 14th 2021, Life for a Child, CLAN, and Insulin for Life will virtually host 'Our Rights to Health in Africa: A Type 1 Diabetes Youth Advocacy Workshop'.

In this exciting upcoming workshop, speakers and panelists will identify what a rights-based advocacy approach looks like for Type 1 Diabetes. During the workshop, we will provide key learnings from country-level case studies and frameworks where loca



Monday 14th June 2021



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advocacy has impacted policy changes in provision of care.

You can expect to come away from the workshop with an understanding of tools and approaches that can be used to drive advocacy initiatives. We will encourage participants to provide feedback on what tools are still needed to strengthen local initiatives.

This workshop will have an African focus, but all global diabetes and NCD advocates are encouraged to join. We are working to ensure that attendance is robust from people living with diabetes, their carers, health care professionals, government officials, to those with general advocacy interests related to the right to health.

This workshop will be held in both French and English, and will be held from:

21:00 - 22:30 EAT 20:00 - 21:30 SAST/CEST 19:00 - 20:30 BST 18:00 - 19:30 GMT

More information on speakers and the workshop can be found here- https://lifeforachild.org/workshop/

Register HERE: https://medpt.zoom.us/webinar/register/WN_9D6VyLPCSg6aNiABMIrHsQ

We look forward to welcoming you June 14th!

Diabetes Youth Camp in Kenya

The welfare of children living with Type 1 Diabetes is a priority of the Kenya Diabetes Management and Information Centre (DMI). Established in 1999 as a not-for-profit medical charity in response to the growing burden of diabetes globally and in Kenya, DMI works towards eradicating preventable diabetes and and achieving its vision of a healthy population, free from diabetes related complications. Between 5000 and 10,000 children are estimated to live with Type 1 Diabetes in Kenya.



DMI champions the care and support of children living with Type 1 Diabetes and is one of the 29 facilities for the Novo Nordisk Changing Diabetes® in Children (CDiC) programme that provides care and life saving insulin for children. DMI supports 570 of the more than 2800 children enrolled in the programme in Kenya. The other facilities are distributed in different regions of the country. DMI believes that all children, including those living with Type 1 Diabetes, should be empowered to achieve their f potential and experience high quality of life. Since the inaugural three-day residential camp for childred with diabetes attended by 13 children aged 8 to 20 years in April 2000, camps continue to be a flags



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activity of the Centre. These camps provide an opportunity for children and adolescents to meet,

interact and learn from each other and from diabetes experts, in an informal fun-filled environment. Through these interactions they come to realize that they are not alone.

Camps are held during school holidays in different regions of the country. In general three camps are held annually with an average of 40 children sponsored to participate in each camp. The children are identified by the CDiC programme leads in the facilities located within the region. While it is the intention for every child to participate in at least one camp this has not been possible due to funding constraints. Priority is given to children newly diagnosed with diabetes and those with poorly controlled diabetes who benefit from the intensive interaction with healthcare providers and other children during the camp. Parental consent is sought for children to attend the camp held in a residential establishment near a local health facility in case of emergencies. Younger children are paired with older peers and are allocated to teams of up to eight children headed by a diabetes educator responsible for monitoring their blood sugar and welfare during the camp. Other camp facilitators include endocrinologists, podiatrists, clinical officers, nurses, nutritionists and counselors.

For the majority of children, diabetes camp is the first time away from home since their diagnosis and the first time interacting with other children living with diabetes. During camp, children are empowered with skills for self-management including: use of glucometers for blood sugar monitoring; recognition, prevention and management of hyper- and hypoglycaemia; use of insulin including injection techniques and storage; foot care; and the importance of nutrition and physical activity in diabetes management. Oral health education, counseling and coping skills, storytelling and experience sharing are also included in the programme with eye, dental and foot checks provided during camp. Participatory teaching and learning methods include peer teaching, group work, role play and creative works. A diabetes knowledge quiz, administered on arrival, is used to identify areas of poor knowledge and is repeated at the end of the camp to gauge changes in knowledge. Young adults with lived experience who have managed their condition well are included as peer facilitators and are instrumental in imparting coping skills to the camp attendees. Children are encouraged to consider Type 1 Diabetes as a condition they can live with and that they can achieve their goals as long they know what to do and are disciplined in following their management protocol. This also helps the children deal with any stigma they may encounter in school and the community.

During camp blood glucose levels are monitored on arrival, pre- and post meals including at bedtime. Improvement in fasting blood sugar concentration is observed in the majority of children during the camp. Children are guided on portion control for optimal glucose control during meal times. It is, however, recognized that many families are limited in the choice of food available. Fun and games are central to the camp programme including time for free as well as structured play such as team sports. This reinforces the importance of physical activity in diabetes management, fosters team building skills and gives the children time to be children. Excursions are also included in the camp programme when possible.



https://www.globalpedendo.org/copy-of-newsletter-2

Over the years, additional funding has enabled one parent or guardian to participate in a separate residential camp held concurrently with their child's camp. This has empowered parents with knowledge and skills to manage their child's condition and provides an opportunity to meet, interact with and learn from other parents. Moreover, this gives them confidence that the knowledge and skills acquired by their children will better equip them to manage their condition.

Diabetes camps have been curtailed due to the prevailing COVID-19 pandemic, however we hope to continue to grow





Catherine Karekezi, PhD

19th newsletter | GPED these essential programmes in tuture.

Catherine Karekezi, PhD (catherinekarekezi@yahoo.co.uk)

Acknowledgement Kenya Diabetes Management and Information Centre acknowledges the support of Ministry of Health, World Diabetes Foundation, Changing Diabetes® in Children, Safaricom Foundation, Johnson and Johnson and diabetes stakeholders in Kenya.

Heat-stability of various insulin types in tropical temperature conditions: New insights towards improving diabetes care



Dr. Marc Maes

According to pharmacopeia, unopened insulin vials must be stored in a refrigerator (2-8°C) while storage at ambient temperature (25-28°C) is usually permitted for the 4-week usage period during treatment. These conditions represent a significant hurdle to insulintreated patients in low resource settings where strict storage at 2-8°C is usually not available in many homes. While several studies have reported significant degradations of insulin preparations under high isothermal conditions, the originality of the study reported by Kaufmann et al. consisted of studying the stability and the biological activity of different insulin preparations stored and used by patients under continuously fluctuating temperatures between 25 and 37° C. These temperatures were chosen following daily measurements performed in a refugee camp in Northern Kenya, run by MSF. Insulin potency was evaluated by high performance liquid chromatography, the 3-D structure by circular dichroism spectrometry and bioactivity by in vitro phosphorylation of the insulin receptor and the aktsignaling intracellular pathway of two different hepatocyte cell lines.

The following insulin formulations used in the field by MSF in low resource countries were studied: rapid, NPH/isophane and premixed rapid/ NPH insulins. Measurements were performed at different time points up to 12 weeks on samples submitted to controlled temperature oscillations in the laboratory and on samples obtained up to 4 weeks from patients from the refugee camp, and compared to formulations kept at 2-8°C during the same time periods.

Under oscillating conditions of temperature, the measured values of insulin quantification ranged between 98.3 and 99.9% of the initial concentrations and were all within the pharmacopeia acceptable range (100 ± 10%) after 4 weeks and even after 12 weeks for the preparations tested under laboratory conditions. In addition, the three dimensional conformation of the mixed insulins as well as their biological activities were conserved under the same fluctuating storage conditions when compared to control samples stored at 2-8°C. Furthermore, no significant difference in stability was found between insulin in pen cartridges and 10 ml vials. The authors conclude that insulin preparations may be kept for at least 4 weeks under fluctuating temperatures at the patients' home even in the absence of access to refrigeration while retaining structural and efficacy integrity. These findings open new perspectives of diabetes care for tropical regions where refrigeration is not always available, affordable, or reliable. does not preclude that the cold-chain of insulin prior to the period of use by the patient should be ensured as mentioned by the authors. This remains an additional challenge for low resource countril **Top**

B. Kaufmann et al. University of Geneva and Médecins sans Frontières (MSF) Geneva, Switzerland <u>https://doi.org/10.1371/journal.pone.0245372</u>

Commentary by Marc Maes, MD, PhD Emeritus Professor of Pediatric Endocrinology and Diabetology Cliniques Universitaires St Luc, 1200 Brussels, Belgium Marc.maes@uclouvain.be

3rd WHO model list of essential in vitro diagnostics (EDL)

Similar to the well known List of Essential Medicines (EML) that was published in 1977, the List of Essential in Vitro Diagnostics (EDL) aims to help member states to develop their own national EDL. The objective of the EDL, first published in 2018, is clarified: "The EDL lists in vitro diagnostics (IVDs) that are recommended by WHO for use in countries to improve access to IVD testing. It aims to serve as a reference for programme and laboratory managers, procurement officers and reimbursement officers who are developing or updating their own national lists of essential diagnostics within the framework of Universal Health Care (UHC). In all cases, countries are expected to decide for themselves which IVDs to select and where to use them, depending on their epidemiology, funding, human resources and infrastructure.

The EDL is also used by UN agencies and nongovernmental organizations to support selection, procurement, supply, donation or provision of IVDs, and can be used by the private medical technology sector to gain insight into the diagnostic priorities and related IVDs needed to address global health issues". In previous lists, tests specifically relevant to



pediatric endocrinology and diabetes were limited to glycosylated hemoglobin (HbA1c) and TSH. Important for the community of pediatric endocrinologists, the 3rd EDL now includes a section on endocrine tests. This year, LH, FSH, cortisol, estradiol, progesterone and prolactin have been added. Additional tests can soon be submitted to be considered for inclusion in the 4th EDL. For additional information, please contact Dr Chanoine who was a member of the Strategic Advisory Group of Experts (SAGE) for the 3rd EDL.

This is an important WHO initiative and GPED members can play a major role, first by submitting additional tests that are relevant to the care we provide as pediatric endocrinologists and second by ensuring that these necessary (although expensive) resources are used by health professionals in the most cost-effective manner. Indeed, in many countries, the cost of in vitro diagnostics ultimately becomes the patient's responsibility.

The 3rd EDL was published on January 29, 2021. It can be found at https://www.who.int/publications/i/item/9789240019102

Jean-Pierre Chanoine, MD PhD Secretary General, Global Pediatric Endocrinology and Diabetes Clinical Professor, British Columbia Children's Hospital Vancouver, Canada

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