

GPED Newsletter

Global Pediatric Endocrinology and Diabetes

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



Dr JP Chanoine

This 2nd GPED newsletter informs you on the many ongoing and future Global Health initiatives in Pediatric Endocrinology and Diabetes !

Following the first newsletter, GPED membership increased by 36 %! In this 2nd newsletter, GPED provides you with more information that is directly applicable to the care of children with pediatric endocrine conditions and diabetes in low income settings.

Contribute to GPED!

There are many opportunities for you to contribute to the development of GPED.

- Become Associate Editor of the GPED Newsletter;
- Share the multilingual resources for families and health professionals that are available in your country on the GPED website;
- Become a translator for the e-Learning curriculum in French, Spanish, Swahili (P4);
- Team up with GPED to improve access to medicines in YOUR country;
- Become a GPED member and contact us to discuss YOUR ideas on how to promote GPED's vision.

Contact us at info@globalpedendo.org for more information.

Mark your calendars!

In 2016, GPED organizes symposia at the ESPE in Paris (Sept 12, 8-10 AM), at the SLEP in Buenos Aires (Nov 10) and at the 4th Symposium on Health Systems Research in Vancouver (Nov 14). More information in the July Newsletter!

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Discuss your difficult clinical cases online with a Pediatric Endocrinologist!



Dr J von Oettingen



Dr JP Chanoine

Pediatric Endocrinologists practicing in low income settings can face difficulties obtaining an expert opinion about a child with a complex pediatric endocrine condition or diabetes. Often, discussion take place by Email and confidential information and/or pictures are being circulated in a non secure manner.

Collegium Telemedicus was originally developed for use by "Médecins sans Frontières" to assist health professionals who wish to start and operate telemedicine networks to deliver health care in remote or low-resource settings. This website has been used successfully in Haiti for the PEEP-H program (see GPED Newsletter #1).

GPED was granted permission to use the program and wishes to offer it to all pediatric endocrinologists living in low income settings, and to their pediatrician colleagues who do not have access to pediatric endocrine consultation locally. It consists of a secure program (requiring a username and a password) that allows the referring physician to provide the relevant clinical information and to upload pictures. It is simple and exists in English, French and Spanish. The clinical question is then forwarded to an expert pediatric endocrinologist who will initiate a discussion around the submission in the appropriate language. Dr Von Oettingen will lead the Collegium Telemedicus initiative for GPED.

Registration is required prior to the first use of the program. To join the program, please go the GPED website (www.globalpedendo.org) where information will soon be available (Expected July 1, 2016).

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International Diabetes Federation *Life For a Child* Program



Dr G Ogle

The International Diabetes Federation "Life for a Child" Program (LFAC) was established in 2000 and is managed from Sydney, Australia with support from Diabetes NSW. The Program is currently helping over 17,000 children and youth with diabetes in 46 countries.

There are approximately 542,000 children under the age of 15 years with type 1 diabetes worldwide. 86,000 new cases are diagnosed each year and numbers are rising between 3-5% per year (IDF Atlas 7th Ed., Brussels 2015). In less-resourced countries, many children quickly die from misdiagnosis or lack of insulin and of experienced medical care. Blood glucose monitoring and diabetes education are often not available. For those who survive, early and serious complications frequently lead to death in young adulthood. Children and young people can be supported to the age of 26 years.

Our vision: No child should die of diabetes

Our mission: To support the provision of the best possible health care, given local circumstances, to all children and youth with diabetes in developing countries, through the strengthening of diabetes services in these countries.

The Program aims to provide: Insulin and syringes, Blood glucose monitoring equipment, Appropriate clinical care, HbA1c testing, Diabetes education, Diabetic Ketoacidosis Awareness Campaign, Age-appropriate diabetes education materials, Health professional training and resources, Technical support for health professionals, Mentoring, Research

For more information on the LFAC Program please go to this link: www.lifeforachild.org. In the next edition LFAC will talk in more detail about their education program.

Dr. Graham Ogle, LFAC General Manager, IDF Life for a Child Program
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ESPE Caucasus & Central Asia School



The ESPE Caucasus and Central Asia School is a successful training initiative in pediatric endocrinology in Caucasus and Central Asia where opportunities for local training are limited. The course is supported by Ferring Pharmaceuticals and coordinated by Dr Rasa Verkauskiene (2nd from right). It is greatly appreciated by both fellows and faculty members. The 1st edition took

place in 2014 in Almaty (Kazakhstan). The 2nd edition was organized by Dr Gulnora Rakhimova, pediatric endocrinologist in Tashkent, Uzbekistan, from October 29 to November 3, 2015. Twenty six fellows from Uzbekistan, Kazakhstan, Tajikistan, Armenia and Russia were selected among more than 40 applications on the basis of clinical and academic experience.

The ESPE Caucasus and Central Asia School was conducted in Russian and English, which was important for students from Central Asia countries with limited knowledge of English. The 4 days course covered pediatric endocrine topics in the form of lectures, interactive clinical case discussions and research projects presentations by fellows. Small group discussions of clinical case presented by teachers were most appreciated by students. Importantly, a novel educational approach – the e-learning program was introduced (see P 4). Important topics were available in Russian thanks to more than 300 hours of translation prior to the course.

Presentations prepared by fellows representing their countries and presented during the gala dinner was an unforgettable experience for all participants. The 3rd ESPE Caucasus and Central Asia School will take place in Baku, Azerbaijan, from October 18 to 23, 2016. Information can be found on the ESPE website.



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Congenital Adrenal Hyperplasia Research, Education and Support (CARE)



D Matas

CARES Foundation, Inc. is a nonprofit organization based in the United States that leads in the effort to improve the lives of the Congenital Adrenal Hyperplasia (CAH) community and seeks to advance quality health care. CARES *through support, advocacy, education and research* represents nearly 8,000 affected individuals, families and healthcare professionals in the United States and more than 70 countries.

Education & Support: CARES offers multiple opportunities for education, support and connecting people affected by CAH from around the world with each other and experts in the field. However, CARES is unable to provide direct access to medicines such as hydrocortisone or fludrocortisone. We provide:

- support network across the US and in 8 countries (Brazil, Canada, Japan, India, Mexico, Pakistan, Philippines, Romania and South Africa) that includes secret Facebook groups and specialized/topic-driven support group leaders
- biannual newsletter

Expert Care: CARES provides access to expert care in CAH. We offer physician referrals to doctors in the US and around the world. Our ASK THE EXPERT online form allows people to directly email our medical director questions. CARES has designated four centers of excellence for CAH in the United States, including New York Presbyterian Weill Cornell Medical Center in New York City, Cohen Children's Hospital at Northwell Health in Long Island, NY, Riley Children's Hospital/Indiana University Health in Indiana and Children's Hospital Los Angeles.

Research: CARES funds research and informs the CAH community of opportunities to participate in research studies (USA only).

Advocacy: CARES Foundation successfully advocated for comprehensive newborn screening for CAH around the world.

Resources: Educational materials, tools for patients and health care providers, and resources for other programs are *freely* available on our website.

Dina Matos, CARES Executive Director

Email: contact@caresfoundation.org

Website: www.caresfoundation.org

Paediatric Endocrinology Training Centre in Africa (PETCA) in Nairobi: Concept and Benefits



G Odundo

The Pediatric Endocrinology Training Centre for Africa (PETCA) is a very successful joint initiative of the Gertrude's Children's Hospital, Aga Khan University Hospital, Kenyatta National Hospital, University of Nairobi Department of Child Health, International Society for Pediatric and Adolescent Diabetes (ISPAD) and the European Society of Pediatric Endocrinology (ESPE). The program activities started running in January 2008 thanks to Funding from the World Diabetes Foundation (WDF). Paediatricians from English-speaking Sub Saharan countries are enrolled on an 18 month fellowship training program. Following an initial 6 months on site training in clinical care and laboratory support under an ESPE tutor, the fellows spend 9 months in their respective countries to develop the diagnosis and management of pediatric diabetes and endocrine diseases. Following an additional 3 months in Nairobi, they take examinations and finalize a thesis that leads to the completion of their fellowship .

The fellowship introduced teams that required the involvement of all health professionals engaged in the care of children with diabetes and other endocrine conditions. This has created networks and sharing of knowledge among the health care professionals with great benefits to the patients under their care. An increase in the number of referrals from adult physicians who in the past were providing the care has been observed as well as in the number of regular follow-up visits and telephone consultations in case of emergency .

To date 54 paediatricians have been trained and their impact at their home institutions has been cost effective relative to training in western hemisphere countries. The experiences learned from tutors coming from well established excellence centres offered the fellows a unique learning environment.

Gordon Otieno Odundo, Chief Executive Gertrude's Children's Hospital

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References: Odundo et al, Int J Endocrinology 2016; Odundo et al, Lancet Diabetes Endocrinol 2016

A Global e-Learning Curriculum in Pediatric Endocrinology and Diabetes for Front Line Health Care Providers in Resource-limited Settings



Stenvert Drop

In a recent survey initiated by GPED, colleagues practicing in resource-limited settings have indicated that there is a need for up to date teaching and instruction material specifically intended for first line physicians (non-specialists) and health workers.

A project proposal was submitted to construct an e-learning portal that would provide:

a. up to date and relevant educational information particularly for resource limited settings through a freely and globally accessible website.

b. interactive education and training material, followed by personal feedback to learners.

Interaction and feedback will be offered mainly through written comments to multiple choice questions but may be extended to direct interactions between students and tutors at a regional and potentially (inter)national/global level.

An exploratory pilot study was performed using short case presentations (vignettes) that highlight clinical issues and pitfalls with emphasis on the three levels of medical health care in resource limited settings: *primary level* (basic or rural); *secondary level* (district and regional hospitals); *tertiary level* (zonal referral hospitals and the main/national referral hospital).

We will construct the lay-out of the e-learning portal using the structure and technology of the espe-elearning.org portal (www.espe-elearning.org) and building on the content of "Practical Pediatric Endocrinology in a Limited Resource Setting", a textbook edited by Dr M Zacharin (see under "Resources" tab on the GPED website). In the chapters and vignettes, specific attention will be paid to addressing each level of care. Chapters and vignettes will be translated into Spanish, French and Swahili by native speaking medical students or colleagues (particularly, but not exclusively from resource limited settings) with ample knowledge of the English language.

We are inviting interested junior and senior pediatric endocrinologists who wish to contribute to this important initiative to contact Dr Drop!

Stenvert L.S. Drop, Sophia Children's Hospital and Erasmus MC, Rotterdam, the Netherlands (former chief editor, espe-elearning.org).

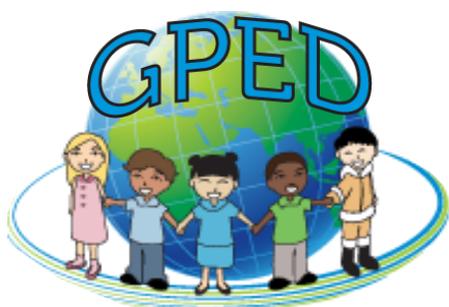
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