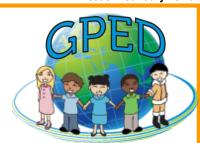
www.globalpedendo.org Issue 1. January 2016

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

Welcome to the first issue of the GPED Newsletter

Global Pediatric Endocrinology and Diabetes (GPED) is a non-profit organization founded in 2010 that aims at improving the care of children living in resource-constrained settings and presenting with endocrine disorders or diabetes through public advocacy, training and education of local health professionals, clinical collaborations and development of translational clinical research.

GPED is endorsed by the regional societies for Pediatric Endocrinology and Diabetes: ESPE, PES, ASPAE, SLEP, ASPED, JSPE, CSPEM, ISPAE, APPES and ISPAD.

The purpose of this quarterly newsletter is to keep health professionals caring for children and families with endocrine disorders and diabetes informed of the initiatives - whether or not initiated

by GPED - that take place around the world n resource-constrained settings in Pediatric Endocrinology and Diabetes.

Become a GPED Member

Registration is free and is performed in 2 easy steps at: www.globalpedendo.org. Members are invited to contribute to - and benefit from - GPED. Initiatives include:

- Promoting access to medicines in Pediatric Endocrinology and Diabetes
- Identifying and translating in various languages clinical resources for health professionals and for families and making them available to GPED members.
- Organizing symposia at annual meetings of Pediatric Endocrine Societies
- Funding permitting, supporting clinically-oriented research projects

GPED welcomes your ideas for future projects!

Contribute to the GPED Newsletter

Are you looking for a collaborator? Are you leading a project that is relevant to Global Health in Pediatric Endocrinology? Do you have information that could be relevant to colleagues facing similar issues around the world? Please let us know!

I wish you a Happy New Year 2016!

Jean-Pierre Chanoine, GPED Secretary General

Inside this issue:

Welcome

Practical paediatric endocrinology in a resource-constrained setting

Fludrocortisone access in Algeria

Caring and Living as Neighbours

Spanish version of a parent's guide on Congenital Adrenal Hyperplasia

Building capacity in Haiti

Training program in Northern Africa

2

Practical Paediatric Endocrinology in a Resource-Constrained Setting: a Novel Textbook



This book edited by Dr Margaret Zacharin aims to provide a practical guide for management of paediatric endocrine problems in a limited resource setting, together with a brief outline of current understanding of the basis for these disorders. It is also a precious resource for general

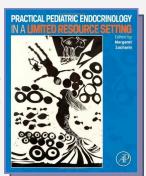
paediatricians working in rural or isolated environments where specialist advice is not easily accessible. A series of scenarios for use by clinicians complements the content, as a teaching and learning tool. A chapter describing basic research techniques and planning, and explaining how to start and complete a research project is provided. Wherever possible we have tried to outline a plan for coming to a likely diagnosis in situations where resources are constrained, while suggesting ways in which more sophisticated technologies may be accessed for

diagnostic confirmation and extension of available tools.

The first revision of this textbook will be available in 2016. A Spanish translation in under way. The book is available at Amazon.com in paper and Kindle versions.

Margaret Zacharin, Editor, Melbourne, Australia.

Email: Margaret.Zacharin@rch.org.au



Issue 1. January 2016 Page 2

Promoting Fludrocortisone Access in Algeria



Dr A Ladjouze

On November 16, 2015, **Drs Asmahane Ladjouze** and **Jean-Pierre Chanoine** (GPED) organized the first meeting for parents of children with congenital adrenal hyperplasia (CAH) at Bab El Oued Hospital (Algiers). This conference was attended by more than 60 parents and their children, by the nurses and the

pediatric endocrinologists at Bab El Oued Hospital, and by Dr Kacimi, Algerian government representative and Deputy Director for the "Pharmacie Centrale des Hôpitaux" (PCH). Topics (presented in French and in Arabic) included a

general review of CAH, long term follow up and outcome, management of fever and access to fludrocortisone. Currently, over 1000 children with CAH are followed in Algeria. Hydrocortisone is available in pharmacies and covered by the generous Algerian Health Care system. In contrast, fludrocortisone is not yet included in the National List of Essential Medicines in Algeria and is not readily available. However, fludrocortisone is present in the list of medicines released by the PCH in Algeria. This means that if a request is sent to the



Ministry of Health, a non-registered product can be imported into Algeria by pharmaceutical companies and covered by the National Health Care system. A parent volunteered to be the support and contact person for all families. We wish to acknowledge the support of Dr Kacimi, who will work with Drs Ladjouze and Chanoine to identify suitable pharmaceutical companies. We hope that this GPED initiative, based on a successful model developed by Dr Armstrong (Caring and Living as Neighbours, CLAN), will soon lead to sustainable access of fludrocortisone in Algeria.

Asmahane Ladjouze, Pediatric Endocrinologist, Algiers, Algeria.

Email: asmahanelad@hotmail.com

Caring and Living as Neighbours (CLAN)



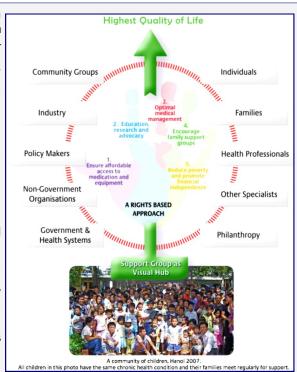
Dr K Armstrong

CLAN (Caring & Living As Neighbours) is an Australian NGO, founded in 2004 by **Dr Kate Armstrong** in response to a growing awareness of the heart-breaking inequity facing children living with Congenital Adrenal Hyperplasia (CAH) in Asia (http://www.clanchildhealth.org/). Five pillars underpin CLAN's strategic framework for action:

- Affordable access to essential medicine and equipment
- Education (of children, families, health professionals, policy makers, national and international community), research and advocacy
- Optimal medical management (holistic approach to primary, secondary and tertiary prevention)
- Encouragement of family support groups
- Reducing financial burdens on families and promoting financial independence

With a rights-based, person-centred, community development approach, CLAN's model demands multisectoral, collaborative focus on local priorities for optimal results. To date CLAN's model has been successfully implemented across a range of chronic health conditions (including CAH, Diabetes, Osteogenesis Imperfecta, Duchenne Muscular Dystrophy, Nephrotic Syndrome and Rheumatic Heart Disease) and countries (Vietnam, Indonesia, the Philippines, Pakistan, Kenya, Nigeria, Algeria).

Kate Armstrong, CLAN President & Founder, Sydney, Australia Email: kate@clanchildhealth.org



Issue 1. January 2016 Page 3

Congenital Adrenal Hyperplasia: a Parent's Guide. Now in Spanish!



Dr Raul Calzada has generously donated his time to translate a guide for parents of children with congenital adrenal hyperplasia (CAH) to Spanish. The book is written for a lay audience and provides

comprehensive,

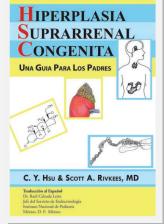
information. It is a great resource not only for Spanish speaking families in

South and Central America, but also for health professionals caring for a CAH child. Our thanks go to Mrs C.Y. Hsu and Dr S. Rivkees who wrote the original book and have agreed to the Spanish translation, and to GPED which sponsored the Spanish edition. This guide is available in English and soon (March 2016) in Spanish at www.Amazon.com and www.authorhouse.com. Free download of the Spanish version

will soon be available on the **GPED** website.

understandable Como padre, encontrarán este libro fácil de comforting comprender, muy complete y reconfortante en su enfoque optimista (J Crawford)

Raul Calzada Pediatric Endocrinologist, Mexico City, Mexico Email: raulcalzada@yahoo.com



Building Capacity in Haiti: a New Program Supported by the Pediatric Endocrine Society



Dr J von Oettingen

Haiti is the poorest country in the Western Hemisphere, and its overall health status ranks among the lowest in the world for many health indicators. The country has no pediatric endocrinologist, and pediatric endocrine education is significantly limited at all levels of training from medical school and residency to continuing medical education. In February 2016, the Pediatric Endocrine Society's International Relations Council will support the novel Pediatric Endocrinology Education Program (PEEP) under the leadership of Dr Julia von Oettingen: PEEP for Haiti will provide training of health professionals at all levels, in collaboration with Haiti's medical schools, residency programs, professional associations, and the Ministry of Health. PEEP will establish a pediatric endocrine curriculum, provide options for formal remote consultation services,

improve continuing medical education, and assess the need, feasibility and cost-effectiveness of a newborn screening program for congenital hypothyroidism in Haiti. Francophone faculty from across North America will offer two-day teaching modules for pediatric residents and medical students five times per year over 3 years, and provide long distance education including video conferences and remote teleconference lectures or case discussions. Trainees will be offered online modules consisting of interactive cases, practice questions and reading materials. To supplement the training, PEEP will look into the feasibility of 2-3 month mini-fellowships in pediatric endocrinology at North American host institutions and, potentially, full fellowship training for selected candidates. In collaboration with Haiti's professional associations, PEEP faculty will organize pediatric endocrinology symposia for local family



practice physicians and general pediatricians. PEEP may offer a unique opportunity to bring pediatric endocrine expertise to Haiti, and in the future, hopefully, a first Haitian pediatric endocrinologist.

Julia von Oettingen, PEEP coordinator, Montreal, Canada Email: Julia.vonoettingen@mcgill.ca

Issue 1. January 2016 Page 4

Paediatric Endocrinology Training in Northern Africa



Dr J Léger

Since 2011, the ESPE Maghreb School, coordinated by **Juliane Léger** and supported by Pfizer, has contributed to the training and education of junior paediatric endocrinologists in the French-speaking countries of Northern Africa (Morocco, Algeria and Tunisia), where opportunities for local training are

limited. This year, the ESPE Maghreb School took place in Algiers between the 17th and 22th November 2015. We warmly thank Dr Asmahane

Ladjouze, Pediatric Endocrinologist in Algiers for organizing this meeting. Her commitment was instrumental in making this 2015 ESPE Maghreb school a great success.

Twenty six trainees attended the program (9 from Algeria, 8 from Tunisia, 8 from Morocco and 1 from the Republic of Congo). The atmosphere of this the 4½ day meeting was one of warm friendship and great enthusiasm, finishing late at





night with the guitar of **Malcolm Donaldson** (left). Similar to the previous years, the format of the meeting consisted of interactive lectures, case presentations from

each student, small group research students and projects to the The program is

26 trainees from Morocco, Tunisia, Algeria and Congo attended this 5th Maghreb School teachers' clinical cases, workshops discussing proposals from the presentation of selected whole group.

supported by a teaching

faculty consisting of ESPE members and of senior endocrinologists from each of the three Northern African countries. The next ESPE Maghreb School will be held in Tunisia in November 2016. Applications will be available on the ESPE website in early 2016.

Juliane Léger, Maghreb School Coordinator, Paris, France Email: juliane.leger@aphp.fr



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

Secretary General:

Jean-Pierre CHANOINE, MD, FRCPC (Academic)
Clinical Professor and Head
British Columbia Children's Hospital
Endocrinology and Diabetes Unit
K4-212, 4480 Oak Street
Vancouver, BC
V6H3V4
Canada

Tel: +1 604 875 2345, ext 5120 Email: info@globalpedendo.org

GPED website: www.globalpedendo.org

Executive Committee:

Jean-Pierre CHANOINE (PES, Secretary General))
Ze'ev HOCHBERG (ESPE, Past Secretary General)
Kerstin ALBERTSSON-WIKLAND (ESPE)
Carine DE BEAUFORT (ISPAD)
Raul CALZADA (SLEP)
Iroro YARHERE (ASPAE)
Vijayalakshmi BHATIA (ISPAE)
Reiko HORIKAWA (JSPE)

Reiko HORIKAWA (JSPE) Xiaoping LUO (CSPEM)

Suttipong WACHARASINDHU (APPES)

Asma DEEB (ASPED)