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**CONTACT
DETAILS**

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MARCH 2007
WWW.APPES.ORG

President's Report

Although 2007 is a preparatory year for the APPES council and Korea local organising committee in planning the 2008 scientific meeting, there are a number of additional activities being addressed by council that will benefit members. The contract to provide electronic access to the journal *Hormone Research* has been signed and very soon members will be contacted when access to the journal through the APPES website will be possible in the members only section. This contract is based upon those with active memberships. For those who are late paying their membership fees it would be prudent to ensure membership is current to allow access to the members only section and *Hormone Research*. The APPES contract with Karger for *Hormone Research* has enabled Associate Professor Chris Cowell to become an associate editor of the journal. There are on-going discussions regarding further positions on the editorial board of *Hormone Research* for several other APPES members.

Council are in the process of formalising the membership of the scientific programme committee (SPC) that will consist of two elected positions; chair and member, as well as president, immediate past president and a member of the local organising committee. The SPC have a critical role in setting the scientific programme for our biennial scientific meeting. All of the positions will be for two years with the exception of the chair who will be appointed for four years to provide some continuity and leadership to the committee. Nominations are currently being sought for the two elected positions (chair and member) from council. If members would like to be nominated for one of these two positions they should contact a council member as soon as possible. Nominations will close on 31 March 2007 with council electing members to the SPC by 30 April 2007.

There are two wonderful opportunities for APPES fellows to attend regional fellows meeting this year. Firstly, sponsorship has been generously provided by Pfizer for eight APPES fellows to attend the Australasian Paediatric Endocrine Group's Fellows' Meeting followed by the APEG Annual Scientific Meeting in Broome, Western Australia from 13 to 18 October 2007. This is a wonderful opportunity arranged by Chris Cowell, our immediate past president, for APPES fellows to enjoy great science in a spectacular location in the tropical north-west of Australia. The eight fellows attending the APEG Fellows Meeting will come from India, Korea, Malaysia, Indonesia, Thailand, Philippines, Singapore and Vietnam. Council will approach the Paediatric Endocrine Societies or groups from these countries to identify a fellow from these countries who will attend the APEG meeting.

Secondly, the 2007 APPES Fellows Meeting will again be sponsored by Merck Serono. The recent merger of Merck and Serono has delayed the identification of the venue and date of the fellows meeting which is likely to be late in the year.

As the year progresses further clinical and educational initiatives will be pursued by Council to enrich the opportunities for APPES members. Council wishes APPES members every success for 2007.

Wayne Cutfield



Wayne Cutfield
APPES President

COUNCIL NEWS

The 2006 - 2008 Council Members are:



President
Wayne Cutfield
Auckland, New Zealand



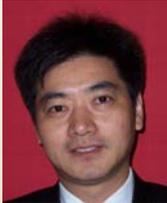
Council Member
Louis Low
Hong Kong, China



Immediate Past President
Chris Cowell
Sydney, Australia



Council Member
Chunxiu Gong
Beijing, China



President Elect
Xiaoping Luo
Wuhan, China



Council Member
Aman Pulungan
Jakarta, Indonesia



Honorary Secretary
Suttipong Wacharasindhu
Bangkok, Thailand



Council Member
Sioksoan Chan Cua
Manila, Philippines



Honorary Treasurer
Craig Munns
Sydney, Australia



Council Member
Sei Won Yang
Seoul Korea



Immediate Past Chairman of LOC
Kitti Angsusinghe
Bangkok, Thailand



Council Member
Keiichi Ozono
Osaka, Japan



Current Representative of LOC
Byung Churl Lee
Seoul, Korea



Council Member
PS Menon
India



Webmaster
Geoffrey Ambler
Sydney, Australia



Council Member
Kah Yin Loke
Singapore

FOCUS ON.....KOREA

Each Newsletter, we plan to bring you news from one of the Member Countries. As we begin planning for the APPES Conference in 2008, we thought it relevant to bring to you news of Seoul, South Korea, where the meeting will be held.

The Korean Society of Pediatric Endocrinology will host the APPES 2008

The Korean Society of Pediatric Endocrinology (KSPE) first started as a study group of pediatric endocrinology in 1987 under the leadership of the late Prof. Hyung Ro Moon (Seoul National University). Aimed at promoting clinical and research activities in the field of pediatric endocrinology, active members such as Prof. Byung Churl Lee (The Catholic University of Korea College of Medicine), Prof. Duk Hee Kim (Yonsei University), Prof. Jeh Hoon Shin (Hanyang University), and Prof. Sei Won Yang (Seoul National University) have worked to stimulate the exchange of knowledge and collaborative studies. Seeing the importance of expanding its research and promoting the best standards of care of children with endocrine disorders and diabetes, the study group was reborn as The Korean Society of Pediatric Endocrinology in October 1995 and Dr. Byung Churl Lee was chosen to serve as the first president.

With the aim to promote the development of and information sharing about pediatric endocrinology, the study group since its establishment in 1987 conducted more than 50 case conferences. At present, the KSPE organizes 2 regular meetings a year and already has successfully hosted 22 spring and autumn meetings, providing an arena for professionals in related field to facilitate scientific exchange and stimulate collaborative studies.

In October 2005, the 10th Anniversary Symposium of the KSPE was held in Seoul and the former president of APPES, Dr. Chris Cowell, as well as Prof. Savage, Prof. Low and Prof. Tanaka have come to congratulate and contribute toward this meaningful meeting (see the picture).

Since June 1996, the KSPE has been publishing 2 journals per year for members to present their scientific papers and exchange the latest achievements as well as covering pertinent and current issues in the field pediatric endocrinology. Currently, the KSPE consists of more than 130 members and among them are active 60 members committed to working together to advance the health of children and youth suffering from endocrine disorders and diabetes by nurturing excellence in health care and education.

The KSPE is interested in promoting cooperative projects for our region, discovering new techniques, and developing new skills to contribute to the world. Many of the KSPE members are active members of Endocrine Society Meeting and since APPES's first scientific meeting in Malaysia in 1999, many of our members have presented their newest medical development and discuss and revise criteria for diagnosis and treatment. Currently, the President of the KSPE, Prof. Sei Won Yang is taking active participation as a committee member of APPES.

At the 4th Asian Pacific Endocrine Society meeting, Seoul was given the honor to be the host of the 5th Biennial Scientific Meeting of the Asia Pacific Pediatric Endocrine Society 2008. Seoul, a city of international conventions, is indeed one of the safest and best convention destinations in the world. Coupled with full support from the endocrine community and from the government, the Local Organizing Committee of APPES 2008 promises to make the utmost preparations for the upcoming meeting with the most prestigious speakers and the outstanding programs ever. To be remembered for all as a memorable academic meeting, the local organizing committee will ensure a meeting that is A: attractive, P: Perfect, P: Pleasant, E: Exciting, and S: Safe in every sense of the word.



10th Anniversary Symposium of the
The Korean Society of Paediatric Endocrinology, 2005

LOC of KSPE

Chair : Prof. Byung Churl Lee

Vice Chair : Prof. Heung Sik Kim, Han Wook Yoo

Executive Secretary : Prof. Kee-Hyoung Lee

Publication : Prof. Byung Kyu Suh

Social Program : Prof. Jin Soon Hwang

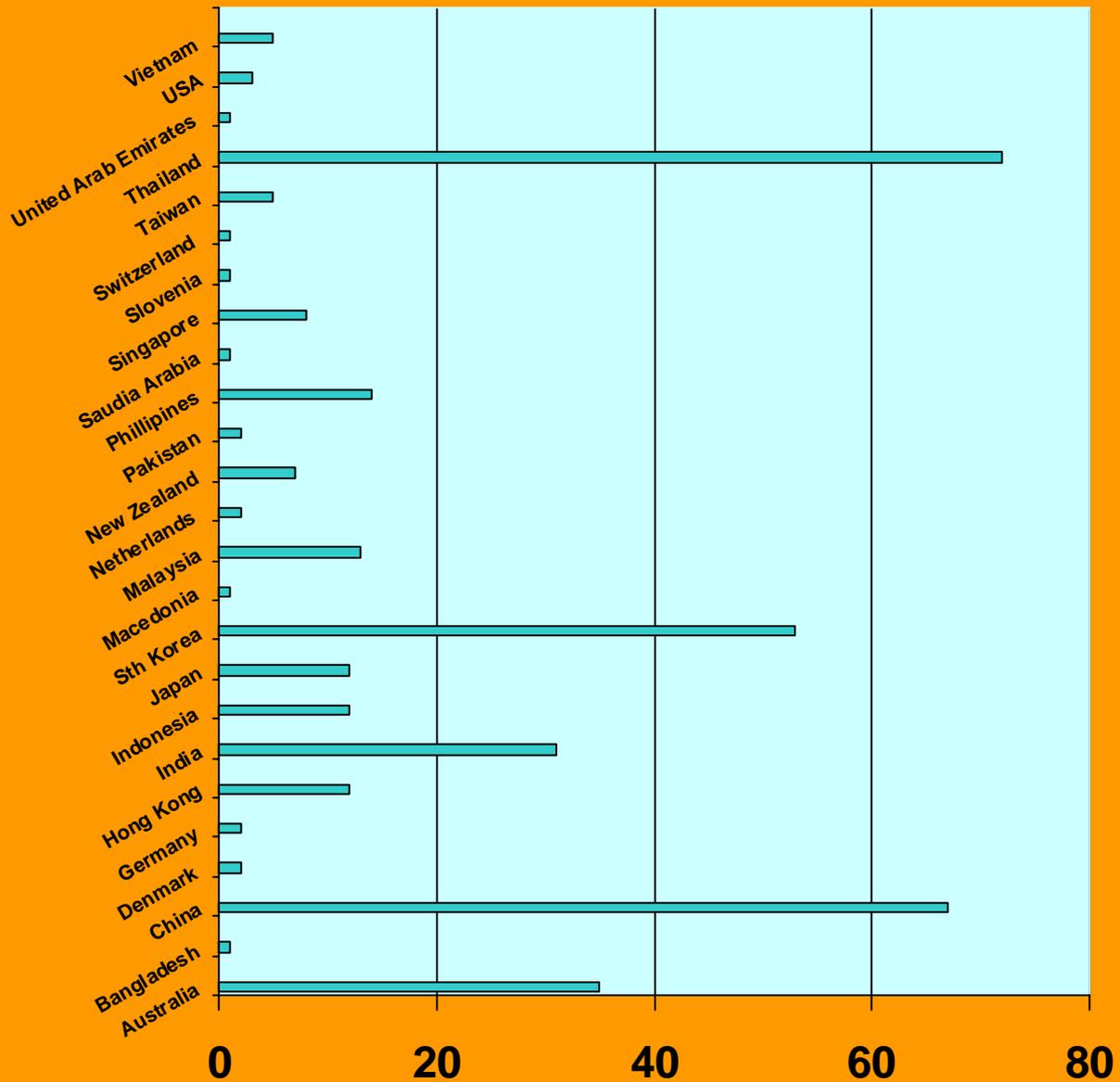
Advisor : Prof. Duck Hee Kim, Jeh Hoon Shin, Dong Hwan Lee

Secretary General : Prof. Sei Won Yang

Scientific : Prof. Ho-Seong Kim

Treasurer : Prof. Choong Ho Shin

STATISTICS FROM 2006 CONFERENCE



Attendance by Country at APPES 2006 Conference, in Pattaya, Thailand.

HORMONE RESEARCH JOURNAL

After many months of discussion and negotiation, APPES Council are delighted to announce access to Hormone Journal On-line for all APPES Members.

To utilise this service, you need to log onto the members area of the APPES website, and then, under RESOURCES, you will find the link to the journal.

NOTE TO ALL MEMBERS

If you are not a financial member for more than 3 months, your access to the members area will be prevented and you will have to contact the APPES Secretariat to pay your membership to be able to gain access once again.



Australasian Paediatric Endocrine Group

OPPORTUNITY FOR APPEES FELLOWS TO ATTEND APEG FELLOWS SCHOOL AND ASM

Due to generous funding from Pfizer and Serono Symposia, there is an opportunity for a Fellow from 8 APPEES countries to attend the APEG Fellows School which begins on the morning of Saturday 13th October and ends on the Sunday afternoon. The Annual Scientific Meeting then begins on the morning of Monday 15th October and finishes with a dinner on the Thursday night, 18th October. Council representatives from each of the selected countries are submitting nominations for persons to attend.

This will be a wonderful opportunity to meet and network with other Fellows from Australia, New Zealand and a number of other countries, and spend time with over 100 delegates at the Annual Scientific Meeting.



ABOUT BROOME

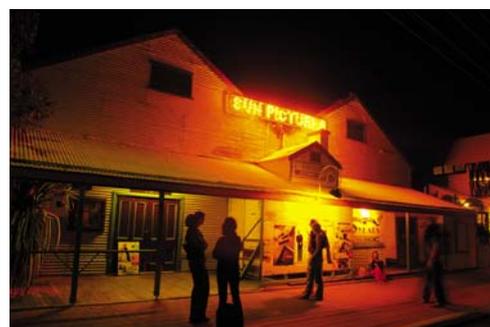
Broome is 2389km north of Perth. Broome is five days straight drive or about three and a half hours flying from Perth. The white sandy beaches, rich red-orange pindan earth, smoky turquoise waters of the mangrove swamps and vivid blues and azures of the ocean are a surreal sight, especially after the harsh and dramatic colours of desert.

The balmy air of historic Broome, is filled with the scent of frangipani. Vibrant colours of bougainvillea amid the unique Broome style buildings that nestle amongst the Coconut palms. The special blend of colonial Australian and Asia cultures has, through many generations, created a style and ambience that is particular to Broome. A romantic vision come true. Here, nothing is more important than the present, you can but slip into "Broome Time

Broome is the outback oasis where the azure waters of the Indian Ocean laps salt white beaches and where ancient pindan cliffs dramatically change colour in the setting sun, going from pink to start red before your eyes. Broome is Cable Beach and ancient dinosaurs footprints. Broome is resort-style accommodation; fragrant frangipani and lazy palm trees. Broome is a fusion of Australian and Asian architecture and people.



For full, and up to date details,
log onto the website:
www.willorganise.com.au/
apeg07 or call the Secretariat
on +61 (0)2 4973 6573



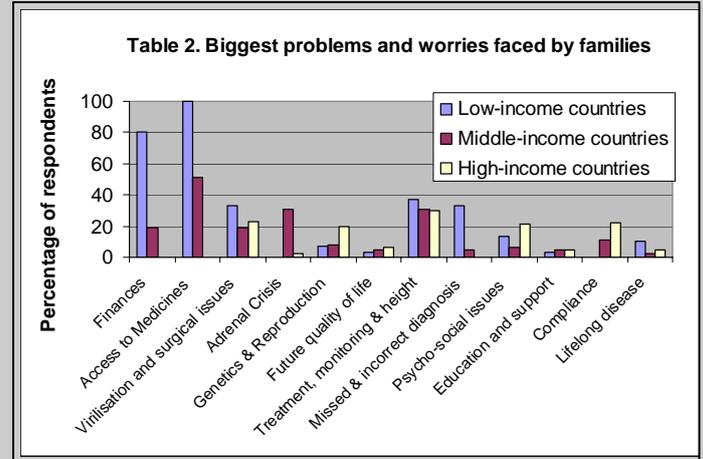
Report to APPEs Members on CLAN's "CAH Survey of Paediatric Endocrinologists", Pattaya 2006.

Health outcomes for children with CAH in the Asia-Pacific region vary enormously from country to country. If we are to address this inequity, then we need to have a better understanding of the current situation overall, identify potential opportunities for change, and work as a united community to effect improvements.

The APPEs 2006 Conference in Thailand was a unique opportunity to capture the unparalleled insights and experiences of Paediatric Endocrinologists from around the region. Sincere thanks to all delegates who participated in this survey; APPEs for supporting CLAN's attendance at the conference, and the Thai local organizing committee for their kind assistance at every step.

Who responded to the survey? (Table 1)

Sixty three doctors from 12 different countries responded. Country response rates appeared to correlate inversely with Gross National Income (GNI): 31% (12/39) of delegates from low-income; 23% (41/178) from middle-income and only 8% (10/132) from high-income countries responded. Two noticeable exceptions were Vietnam and the Philippines, where CLAN has been collaborating successfully with doctors and CAH Support Groups for several years to improve health outcomes.

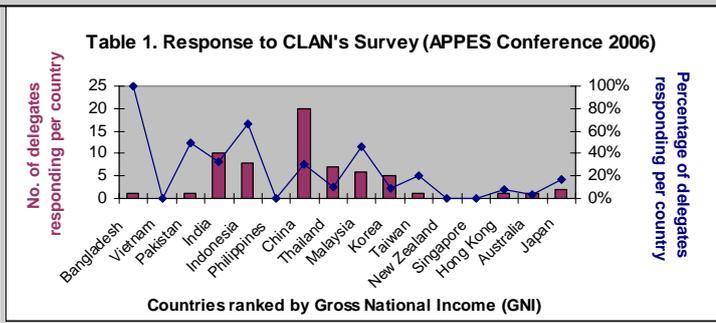


Are there adequate educational resources available?

There was widespread acknowledgement of the need for more educational resources on CAH to be available to families in local languages. Since the APPEs conference [Professor Garry Warne's booklet on CAH](#) has been made available on the internet in Chinese characters, and will soon also be available in Bahasa Malay, Bahasa Indonesian and Tagalog.

How can CLAN help your CAH patients and families? (Table 3)

Delegates from low-middle income countries suggested CLAN could assist with: affordable access to medication; financial support for families; local CAH Clubs; and educational resources. Happily, these are, in fact, all key to CLAN's *modus operandi* to date. In general terms, doctors from high-income countries saw less of a role for CLAN in helping their patients



How many CAH patients do you have?

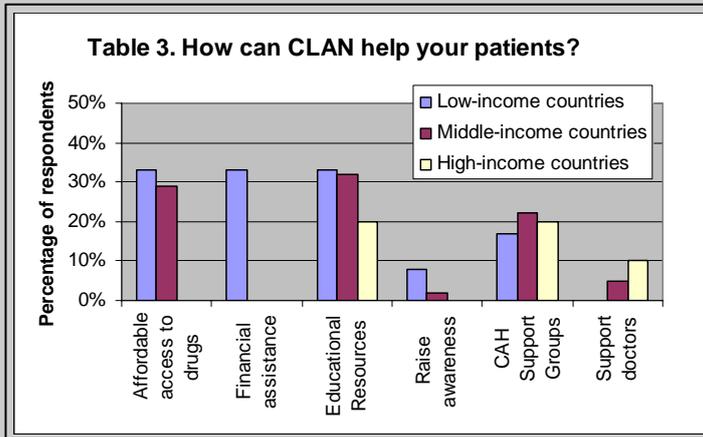
Whilst 85% of delegates estimated the number of children with CAH under their direct care, only 25% attempted an estimate of the total number in their country. A country's total population did not correlate well with number of children estimated to be living with CAH: GNI and registration status of hydrocortisone and fludrocortisone were usually better predictors. Based on all data available, CLAN would estimate there are over 5,500 children living with CAH in the Asia-Pacific region.

Are hydrocortisone and fludrocortisone affordably available?

There is an **urgent** need for registration of hydrocortisone and fludrocortisone in Bangladesh, Pakistan, Indonesia and the Philippines, with variable reports of access in China and Thailand. Conversely, all delegates from the 8 highest income countries reported full registration and affordable access to hydrocortisone and fludrocortisone tablets for their patients.

What are the biggest problems and worries facing families? (Table 2)

Finances, access to medication, missed and incorrect diagnoses and adrenal crises were ranked by doctors from low-middle income countries as the biggest issues for families, correlating well with data from other surveys. Concerns with virilisation, surgical issues, treatment, monitoring and final height were more broadly shared.



What can we draw from this data?

1) Procurement, reliable supply and affordability of hydrocortisone and fludrocortisone in **all** countries needs to be an urgent priority for our region. Registration negates the role of the black market, with a profound and instant impact on cost, access and quality. Regional networking could facilitate fair and equitable pricing, and empower doctors to help their CAH patients access the cheapest, highest quality drugs and health care possible.

2) Educational resources for patients and families can be extremely useful tools, yet onerous to produce and translate. Creating a shared "knowledge bank" of such resources at a regional level like APPEs would take the burden off individual practitioners, and enable wider use of quality resources and officially en-



dorsed translations. Local CAH Support Groups are an effective forum for disseminating such resources, and the internet an increasingly relevant tool for connecting support groups, patients, families and doctors (eg. www.cahclan.org).

3) Data collection is another challenge. Simple surveys of families, and CAH databases collated by doctors, hospitals and countries must be a priority. Estimates of basic statistics could then be used to raise awareness, lobby various stakeholders and develop strategies for change.

4) Collegial collaboration at international paediatric endocrinology forums to explore these issues in more detail would be extremely useful. Whilst this survey highlighted problems specific to CAH, virtually all of the discussion points could equally apply to any of the other common chronic endocrine conditions of childhood.

Conclusion

We can choose to accept inequity as a natural and inevitable consequence of global politics and wealth distribution, or we can try to find simple, sustainable ways to effect change. Whilst health care professionals alone should not carry the burden of transformation, it is important that we do not see ourselves as impotent, but rather, as a united force, capable of great things.

Gross National Incomes based on World Bank data: <http://web.worldbank.org/WBSITE/EXTERNAL/DATASTATIS-TICS/0,,contentMDK:20535285~menuPK:1192694~pagePK:64133150~piPK:64133175~theSitePK:239419,00.html>

Armstrong KL, Henderson C, Hoan NT, Warne GL. Living with Congenital Adrenal Hyperplasia in Vietnam: a Survey of parents. *Journal of Pediatric Endocrinology & Metabolism*, 19, 1207-1223 (2006).

Chan-Cua S, Fernandez E et al. Unpublished. Survey of parents at Filipino CAH Support Group meeting, Manila, Dec 2005.

“Healthier children, better world!”

Royal Children’s Hospital International and South-East Asia.

In 1998, the Royal Children’s Hospital Melbourne (RCHM) moved to increase its involvement in international child health development projects by establishing a new department, RCHI, to help it build strong links and collaborative projects with hospitals and NGOs in the Asia-Pacific region. RCHI is funded from philanthropic sources, principally Atlantic Philanthropies, and relies entirely on external funding to support every project. Projects that benefit the poor and disadvantaged are preferred and most projects have been in education and training, but also in health service planning. All clinical disciplines – medical, nursing and Allied Health – have the opportunity to participate and multidisciplinary teams are formed to provide in-country training. As an endocrinologist, I have had the opportunity to take a special interest in the development of paediatric endocrinology in Vietnam, a country I have visited dozens of times over the past 12 years. Congenital adrenal hyperplasia seemed to present a particular opportunity for a strategic approach and in this, RCHI has been fortunate in being able to collaborate with CLAN – CAH Living as Neighbours - which was formed in response to articles we wrote describing the situation for parents and patients in Hanoi. Due to poverty and the unavailability of hydrocortisone and Florinef except on the black market, parents were hard pressed to provide medications for their children on a regular basis and for the children of the rural poor, an early death was almost inevitable. Our strategy with CLAN has focused on establishing parent support groups, obtaining donations of medications from pharmaceutical companies (Bristol Myers Squibb and Alphapharm), advocacy resulting in the registration of Florinef and the partial registration of hydrocortisone in Vietnam, translating educational material, providing training for doctors, preparing wall posters to raise awareness of CAH as a cause of ambiguous genitalia, and advocacy to have 17OHP testing made available in both Ho Chi Minh City and Hanoi. Long term solutions to the burden of poverty remain to be found.

In addition, RCHI has provided train-the-trainer courses in Advanced Paediatric Life Support for Vietnam and Cambodia, in paediatric nurse education for Vietnam and India, and in Infection Control for Vietnam. We assisted the National Hospital of Pediatrics in Hanoi by advising on the preparation of the health services plan and the master plan of staff training for a complete redevelopment of the hospital, and we assisted the Hue Central Hospital Cardiovascular Centre by coordinating the training of 111 staff at 5 different locations in three countries. In Indonesia, RCHI is collaborating with the University of Melbourne and the University of Gadjah Mada in Yogyakarta in a 3-year, World Vision funded post-tsunami health system reconstruction and development project in Aceh. We established a combined Vietnam-Australia program of assistance to Laos, which has been very successful.

*Garry Warne, Director, RCHI and Senior Endocrinologist
Royal Children’s Hospital Melbourne, Australia
(garry.warne@rch.org.au)*



Children in Hoi An

APPES COUNCIL

The following council were elected into their position at the APPES Biennial Meeting in Thailand. See page 2 for more details.

EXECUTIVE COUNCIL

President:	A/Prof Wayne Cutfield	New Zealand
Secretary:	Dr Suttipong Wacharasindhu	Thailand
Treasurer:	Dr Craig Munns	Australia
President Elect:	Prof Xiaoping Luo	PR China
Immediate Past President:	A/Prof Christopher Cowell	Australia

COUNCIL

Dr Aman Pulungan	Indonesia
Prof Louis Low	Hong Kong
Prof Keiichi Ozono	Japan
Dr Sioksoan Chan-Cua	Philippines
Prof Sei Won Yang	Korea
Prof Byung Churl Lee	Korea
Prof Kitti Angsusingha	Thailand
A/Prof Kah Yin Loke	Singapore
Dr Geoffrey Ambler	Australia
Dr PS Menon	India
Dr Chunxiu Gong	PR China

An invitation is extended to all APPES members to submit news for the newsletter. Each year, the newsletter will be published in March, June, September and December, with an additional 'conference issue' each year of the APPES Scientific Meeting.

If you would like to submit articles or photos, please do so via email on appes@willorganise.com.au

Future Events

2007:

April 19-22

CPEG 2007 Scientific Meeting
London, Ontario, Canada
<http://cpeg-gcep.blogspot.com>

June 2 - 5

ENDO 2007: Toronto, Canada
www.endo-society.org/educationevent

June 22 - 26

American Diabetes Association 66th Scientific Sessions: Chicago, USA
www.diabetes.org/for-health-professionals-and-scientists/profed.jsp

June 27 - 30

46th ESPE Meeting: Helsinki, Finland
www.congrex.com/espe2007/
Email: espe2007@congrex.se

Sept 2 - 5

ESA ASM, Christchurch Convention Centre, New Zealand

Sept 26-29

ISPAD: Berlin, Germany
www.ispad2007.com
Email: kordonouri@hka.de

Oct 13-17

19th Annual SLEP Meeting, Mar del Plata, Argentina
www.slep.com.br

Oct 15 - 18

APEG Annual Scientific Meeting
Broome, WA, Australia
Email: apegasm@willorganise.com.au
www.willorganise.com.au/apeg07

2008:

March 1-2

Prader Willi Syndrome Scientific Workshop & Conference
Wellington, NZ
www.pws.org.au/conference.html
Email: conference@pws.org.au

Aug 12-16

34th Annual Meeting of ISPAD Durban, South Africa
www.ispad2008.com

Sept 20 - 23

47th ESPE Meeting: Istanbul, Turkey
www.espe2008.org/
Email: espe2008@congrex.se

Oct 29 - Nov 1

5th Biennial APPES Scientific Meeting Seoul, Korea
Email: appes@willorganise.com.au

Nov 8-12

13th International Congress of Endocrinology, Rio de Janeiro, Brazil
www.ice2008rio.com

2009:

Sept 9-12

8th Joint ESPE/LWPES Meeting, New York, USA
www.lwpes-espe2009.org

Sept 16-19

34th Annual Meeting of ISPAD Ljubljana, Slovenia
E-mail: tadej.battelino@mf.uni-lj.si

If you have a meeting you would like to add to this listing, please email the APPES Secretariat on appes@willorganise.com.au with the following details:

- Name of Conference, City/Country where being held, Website Address and Contact Email Address