
Subject: FW: 16th Expert Committee on the Selection and Use of Essential Medicines

From: Lilea Propadalo **Sent:** 16 September 2007 06:17

To: emlsecretariat

Subject: 16th Expert Committee on the Selection and Use of Essential Medicines

For the Attention of:

The Secretary of the Expert Committee on the Selection and Use of Essential Medicines
Policy, Access and Rational Use
Department of Medicines Policy and Standards (PSM)
Health Technology & Pharmaceuticals
World Health Organization

Dated: 16 Sept 2007

On behalf of: The CAH (Congenital Adrenal Hyperplasia) Community (being a member thereof) and CLAN (CAH Living as Neighbours).



Re: Selection and Use of Essential Medicines for Children

With Particular reference to: **Section 18/subsection 18.1 (Adrenal Hormones and synthetic substitutes)**

It was noted within the draft listing of medicines for consideration, that this section (amongst others within Section 18) were considered to be irrelevant to children under the age of 12 years and were therefore not included in the EMLc. It was also noted that subsection 18.1 of 'Adrenal Hormones and synthetic substitutes' be included under the complementary Section and that review be made with consideration of a proposal for the listing of Fludrocortisone.

It is unfortunate that adrenal conditions may happen to us all at any time of life. Perhaps the most significant time is that of infancy and childhood when the treatment we receive is paramount to the improvement of our health and the very continuance of our existence. It is at this time particularly that, if insufficient or incorrect treatment is undertaken, the consequences are lifelong.

I believe that by making the ESSENTIAL medicines taken for adrenal insufficiency (CAH being one of many forms) available as part of an ongoing list it emphasises the importance of these medications as being of lifesaving value to the children that face adrenal insufficiency. It asks Practitioners to also recognise the necessity of accurate and efficient treatment, merely by their presence within.

As a group, CLAN will monitor the WHO site for the next subcommittee meeting by which to make formal application for consideration of these vital medications. Unfortunately, we were unaware of the application process until we were past the closing date.

At this stage therefore we will ask that if discussion is undertaken for the inclusion of Fludrocortisone (presumably in its function of aldosterone replacement), that consideration also be given on an informal level of other adrenal replacement medications such as:

Hydrocortisone - oral medication (both liquid for infants and tablets for children) for cortisol replacement

Hydrocortisone - intramuscular and intravenous available vials for injection for the treatment of acute adrenal crisis

Prednisolone/Prednisone - oral medication for cortisol replacement in children requiring stronger treatment

Fludrocortisone - oral medication (both liquid for infants and tablets for children) for aldosterone replacement

(Liquid and oral noted depending on availability.)

CLAN was developed as a result of the need of children with adrenal insufficiency to access affordable and quality medication and treatment in less developed regions of the world. It has, along with its founder, Dr Kate Hansen, had an incredible impact upon the lives of hundreds of families in Vietnam, The Philippines and, more recently, Indonesia. Without recognition of the essential nature of the medications these children take on a daily basis to maintain their wellness and enable their bodies to, not only function correctly to maintain their health, but also to develop appropriately for their chronological age and developmental stage of life. Recognition, acceptance and follow-through of correct treatment in childhood may enable them to: reach their height potential, develop into puberty at the appropriate stage of their development and later, lessen the risk of invasive procedures and possibility of surgical procedures for virilisation and also (sometimes most importantly), to ensure their fertility, self-esteem and peer acceptance within the communities in which they live, as a consequence of providing cortisol/aldosterone replacement on a daily basis.

On a personal note, I consider these medications vital and lifesaving and that I am living proof of this fact. Diagnosed at 5, without medication, as time progressed, I am truly not sure what my life's expectations would have been. The situation for children actually picked up at birth is even more dire, as many females diagnosed at birth have side-effects of virilisation that require surgical intervention to enable them to grow and live as a fully-functioning child and adult. This situation is in addition to the already difficult situation faced by families of adrenal crisis and the impacts of living with adrenal insufficiency on a daily, and lifelong basis.

My treatment regime and the success thereof, has enabled me to have two children thus far (a 3rd on the way), when my parents were advised initially that reproductive expectations were low. The success my family and others have experienced, has given great hope to the wider community and parents of children facing adrenal insufficiency now in their lives. It is only through the advancement of treatments and the recognition around the world of the essential and lifesaving nature of these medications, that this improvement in the condition of children with adrenal insufficiency may continue.

Thank you for giving considerations to my comments. I hope to submit a formal application at your next subcommittee meeting.

Regards

Lilea Propadalo (Mrs)