

Vancouver November 29, 2022

Jean-Pierre Chanoine, MDPH  
Secretary General  
Global Pediatric Endocrinology and Diabetes  
Vancouver

To: Expert Committee on the Selection and Use of Essential Medicines  
Children's Essential Medicines List  
World Health Organization  
Geneva

To Whom It May Concern,

**Re: Application for Inclusion of oral phosphate salts in the WHO EMLc for the management of hypophosphatemic rickets**

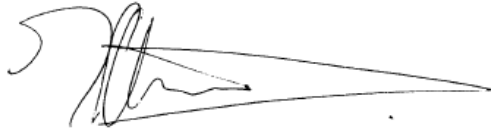
Global Pediatric Endocrinology and Diabetes (GPED) is a non-profit organization and a Canadian charity established in 2010. GPED aims at improving the care of children presented with endocrine disorders or with diabetes living in low and middle-income countries (LMICs) through public advocacy, training and education of local health professionals, clinical collaborations and development of translational clinical research.

I am writing this letter as Secretary General of GPED. A similar letter supporting the inclusion of calcitriol and 1 alfacalcidol has been sent to the Executive committee. These 2 letters emphasize the importance of providing both phosphate salts and calcitriol/1 alfacalcidol for the management of hypophosphatemic rickets. Indeed, the clinical signs (rickets, bone deformities, poor growth, bone pain) are secondary to phosphate loss as well as to the inability to hydroxylase Vit D in the position 1.

The Executive Committee of GPED has reviewed the submission and fully supports it. Although to our knowledge there are no published cost-effectiveness studies, the cost of these medicines, that significantly decrease morbidity and have been used for many years in high-income countries, is modest and should not be an obstacle to their inclusion in the EMLc. Patients with hypophosphatemic rickets are usually followed by pediatric endocrinologists or by pediatricians in specialized centers, and as such, we suggest that the proposed medicines should be included in the complementary listing of the EMLc.

GPED respectfully suggests that the Expert Committee consider adding phosphate salts as an essential medicine, together with calcitriol/1 alfacalcidol, for the management of hypophosphatemic rickets in children.

Sincerely,

A handwritten signature in black ink, appearing to read 'JP Chanoine', with a long horizontal stroke extending to the right.

Jean-Pierre Chanoine, MD  
Secretary General, Global Pediatric Endocrinology and Diabetes

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Wellington, November 15, 2022

Esko Wiltshire, MB ChB MD DipObst DipPaed FRACP  
Chair, International Consortium of Pediatric Endocrinology & Diabetes Societies (ICPE)  
Professor in Paediatrics and Child Health  
University of Otago Wellington and Te Whatu Ora, Capital and Coast Health  
New Zealand

To: Expert Committee on the Selection and Use of Essential Medicines  
Children's Essential Medicines List  
World Health Organization  
Geneva

To Whom It May Concern,

**Re: Application for inclusion of oral phosphorus (phosphate salts) in the WHO Model List of Essential Medicines for children (EMLc) (April 2023)**

I am writing this letter of support as Chair of the International Consortium of Pediatric Endocrinology & Diabetes Societies (ICPE).

This consortium was founded in September 2015 with the goal of increasing collaborations at all levels between Pediatric Endocrinologists across the five continents. It regroups all major regional Pediatric Endocrine Societies, as well as the International Society for Pediatric and Adolescent Diabetes (ISPAD) and Global Pediatric Endocrinology and Diabetes (GPED): the Arab Society for Paediatric Endocrinology and Diabetes (ASPED); the Asian-Pacific Pediatric Endocrine Society (APPES); the African Society for Paediatric and Adolescent Endocrinology (ASPAE); the Chinese Society for Pediatric Endocrinology and Metabolism (CSPM); the European Society for Paediatric Endocrinology (ESPE); the Indian Society for Pediatric and Adolescent Endocrinology (ISPAE); the Japanese Society of Pediatric Endocrinology (JSPE); the Pediatric Endocrine Society (PES), the Latin American Society for Pediatric Endocrinology (SLEP) and the Russian Paediatric Endocrinology Group.

ICPE, through their regional societies, represents more than 5,000 pediatric endocrinologists across the 5 continents.



Phosphate salts are used in children for the management of hypophosphatemic rickets in order to correct the chronic phosphorus loss through the kidneys (a highlight of the condition). As pediatric endocrinologists, we see the consequences of poorly treated hypophosphatemic rickets on bone pain and growth, as well as the difficult surgeries that have to be performed. The resulting decrease in morbidity associated with hypophosphatemic rickets makes them an essential medicines for these children. As such, this affordable medicine should be available in all countries regardless of their income.

ICPE members fully support the inclusion of phosphorus, given orally as phosphate salts in the EMLc.

Yours Sincerely,

Esko Wiltshire  
ICPE Chair

December 16, 2022

24th Meeting of the Expert Committee on the Selection and Use of Essential Medicines  
World Health Organization  
Geneva, Switzerland

Dear Colleagues,

I am currently President of the **Endocrine Society**. The **Endocrine Society** is an international organization of over 18,000 endocrinologists that includes clinicians and basic scientists. It promotes breakthroughs in scientific discovery and medical care through publishing in its peer-reviewed journals, hosting an annual scientific meeting, creating resources and educational materials to help clinicians and investigators accelerate the pace of scientific discovery and translation of the latest science into clinical care, advocating for appropriate support and policies that benefit healthcare providers and patients, and educating the public about hormones and the roles that endocrine scientists and clinicians play in achieving optimal public health. The Endocrine Society publishes Clinical Guidelines for clinical care and these Guidelines discuss many of the medications being submitted now for inclusion in the recommended medicines for WHO.

The Endocrine Society has worked from the beginning with the current committee in bringing to the WHO this new list of medications that are felt to benefit patients with endocrine diseases world-wide. Dr. Molitch, a member of the Endocrine Society, is Co-Chair of this committee. It is important for the WHO to understand that this committee truly has world-wide representation, including Drs. Chanoine, the Chair, and Dr. von Oettingen from Canada, Dr. Molitch, from the USA, Dr. Villarroel from Bolivia, Drs. Ewen and Beran from Switzerland, Drs. Kalra and Paulose from India, Dr. Abodo from the Ivory Coast, Dr. Karekezi from Kenya, Dr. Ramala from Tanzania, Dr. Donahue from Australia, Dr. Junfen Fu from China, Dr. Besancon from Mali, Dr. de Beaufort from Luxembourg, and Dr. Gary from the UK. In addition, the committee included not only endocrinologists (Drs. Chanoine, Molitch, Villarroel, von Oettingen, Kalra, Abodo, de Beaufort, Donaghue, Paulose, Ramalya, and Fu) but also economists (Drs. Ewen and Beran), pharmacists (Drs. Gray and Karekezi), and a dietitian (Dr. Besancon). The endocrinologists were equally divided into pediatric and adult endocrinology.

The applications for these new medications were discussed in depth by this committee to determine both their health benefits, potential adverse effects, and costs. The committee was well aware of cost and logistical limitations of some of the medications in various countries but felt that these medications should be part of the core or complementary lists for adults or children of recommended medications for the upcoming revision.



The Endocrine Society hereby supports the **Application for inclusion of phosphorus (phosphate salts) for the management of hypophosphatemic rickets** (in conjunction with Calcitriol (1,25-dihydroxy-cholecalciferol) or alfacalcidol (1 $\alpha$ -calcidol)).

The Endocrine Society agrees that phosphate salts are currently used clinically in many countries and have already proved to be of great benefit to thousands of patients. The Society enthusiastically supports their inclusion in the upcoming WHO Lists of Essential Medicines.

Sincerely,

Ursula Kaiser, MD  
President  
Endocrine Society



12/01/22

24th Expert Committee on the Selection and Use of Essential Medicines  
World Health Organization  
Geneva

Dear Committee Members,

I am writing this letter on behalf of members of our Scientific Advisory Board, regarding the application for the inclusion of Phosphorus in the WHO Essential Medicines- children's List (EMLc), for use in hypophosphatemic rickets, submitted by the Global Pediatric Endocrinology and Diabetes society.

We support this effort by the GPED, noting the importance of using both phosphate and alfacalcidol/calcitriol available for effective management of XLH (X-Linked Hypophosphatemia)

Thank you for your consideration.

Sincerely,

*Susan Faitos*  
Susan Faitos  
Executive Director  
The XLH Network, Inc.