Cooley's Anemia
FOUNDATION
Leading the Fight Against Thalassemia

April 7, 2023

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

Re: A.13 Deferiprone - transfusional iron overload - EML and EMLc

Dear Expert Committee:

As the National Executive Director of the Cooley's Anemia Foundation, the premier advocate for the thalassemia community in the United States of America, I am writing in support of the above-referenced application to include the oral chelator deferiprone on the WHO Model List of Essential Medicines and the WHO Model List of Essential Medicines for Children.

Individuals born with severe forms of thalassemia require lifelong blood transfusions as often as every two weeks and must also undergo daily chelation therapy to remove excess iron from these transfusions as well as from excess iron obtained from other sources. Deferiprone was approved for use by the U.S. Food and Drug Administration in 2011 and the U.S. community experience demonstrates that deferiprone is an excellent chelating option for those thalassemia patients with transfusional iron overload.

Deferiprone is especially advantageous when treating a patient who is experiencing cardiac iron loading, which has historically been the leading cause of death among thalassemia patients in the U.S. While there are some potential side effects, proper monitoring by the physician can ensure that the drug is used safely.

The Foundation has heard from many patients in the U.S. whose cardiac health was improved, often dramatically, due to use of deferiprone. In addition, the chelator is quite effective at removing iron from other areas of the body as well.

I cannot strongly enough urge WHO to add this important chelating option to the EML and EMLc.

Thank you,

Sincerely,

Craig Butler

Craig Butler
National Executive Director

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