United States House of Representatives
Committee on Energy and Commerce, Subcommittee on Health

Hearing on

"Examining the Advancing Care for Exceptional Kids Act"

Written testimony submitted by
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Chairman Pitts and Ranking Member Greene,

Thank you for the opportunity to provide written testimony for the hearing entitled, "Examining the Advancing Care for Exceptional Kids Act." I am writing to you today on behalf of the Cooley's Anemia Foundation (CAF), which is dedicated to serving people afflicted with various forms of thalassemia, most notably the major form of this chronic, genetic blood disease, Cooley's Anemia/thalassemia major. Founded over 60 years ago, CAF's mission is to advance the treatment and cure for this fatal blood disease, to enhance the quality of life of patients and to educate the medical profession, trait carriers and the public about Cooley's Anemia/thalassemia major.

Thalassemia is the name for a group of blood disorders. There is a wide spectrum of severity for patients with thalassemia, ranging from mild to extremely severe, though many patients must receive regular blood transfusions to make up for the body's inability to effectively produce hemoglobin. These regular blood transfusions cause a number of health concerns and risks for patients due to the resultant excess of iron in patients, requiring the use of iron chelators to normalize their iron levels. Patients with thalassemia face a number of issues related both to the management of their disease and as a response to the regular blood transfusions which are necessary for many patients.

For transfusion-dependent children, many symptoms are the consequence of iron overload, a consequence of their regular blood transfusions. Symptoms of iron overload can include chronic fatigue, liver disease, abdominal pain, heart problems, joint pain, or even early onset osteoporosis. Though the quality and length of life has greatly improved for the thalassemia patient community, many patients will remain dependent on regular blood transfusions and impacted by their condition for the entirety of their lives.

Many thalassemia patients receive care through Medicaid due to the regularity of their healthcare needs and the overwhelming associated costs. As a consequence, the ACE Kids Act has the potential to transform care for these patients in a radical and positive way. As with

many chronic conditions, that which affects a child affects the whole family. Increasing availability of such services as care coordination, comprehensive care management, transitional care and follow up, and patient and family support, will help allow patients and their families to continue to live the healthiest and happiest lives possible while optimizing their access to care.

The Cooley's Anemia Foundation believes that in those states that implement it, the ACE Kids Act will be very beneficial to improving the quality of life for the patients and the families involved. We are proud to support the legislation and hope to see it fully implemented in the states.

Thank you very much for the opportunity to provide testimony regarding this vital and transformative legislation. With any additional questions, please do not hesitate to contact me at cbutler@thalassemia.org.