

## Outreach Updates

### Cooley's Anemia Foundation:

If you haven't already, join the Cooley's anemia Foundation. This organization helps raise money for thalassemia research, patient support groups, and they have amazing events. Please visit [www.Thalassemia.org](http://www.Thalassemia.org)

### Thalassemia Women's Group:

In June, we had our first thalassemia women's group meeting. Kristen Montesanto our social worker facilitated the first session. We are planning to hold another meeting in the fall. We're hoping to offer a "phone in" option to for folks who would like to participate but unable to attend



Cooley's anemia Foundation (CAF) Meeting: Several patients attended the 2019 Cooley's anemia Foundation meeting in San Francisco. One of our patients led a Cognitive Behavioral Therapy Thalassemia Workshop. Another patient was selected for the Thalassemia International Federation (TIF) meeting in Germany in October.

### Research Corner

Gene therapy is a potentially curative treatment in clinical trials in the United States and is currently conditionally approved in Europe. The European Commission approved gene therapy for eligible patients over the age of 12 with non  $\beta^0/\beta^0$  transfusion dependent thalassemia patients.

We have many research trials underway please visit our website for more information.

## NYP-Weill Cornell Thalassemia Comprehensive Center Quarterly Newsletter Volume 1

Welcome to the NYP Weill Cornell Comprehensive Thalassemia Center – check out our website at <https://thalassemia.weill.cornell.edu>

Get up to date information about our center and what we do! On the website there is a link to contact us directly. You can sign up for our newsletter and receive notifications of our activities!