

## **Annual Report – FY 2017**

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### **Statement of Purpose**

The Cooley's Anemia Foundation is dedicated to serving people afflicted with various forms of thalassemia, most notably the major form of this genetic blood disease, Cooley's anemia/thalassemia major.

### **Mission**

The mission of the Cooley's Anemia Foundation is to increase life expectancy and enhance the quality of life for those impacted by thalassemia, a class of genetic blood disorders, most of which require regular blood transfusions and aggressive management of chronic iron overload, the predominant cause of early death. We do so by funding medical research to advance treatment and curative approaches, by supporting and advising patients and their families and advocating on their behalf and by educating medical professionals and the general public.

Every day, we strive for longer and healthier lives for all patients with thalassemia until a universal cure is found.

As the leading voice for the thalassemia community in the United States, CAF continues to make its presence felt across the country. Some of our many accomplishments during FY 2017 (July 1, 2016 – June 30, 2017) include:

**2017 Patient-Family Conference.** The Cooley's Anemia Foundation shifted the dates of its Patient-Family Conference to July 7-9, 2017 in Hyattsville, MD. As a result, the Conference itself fell outside the bounds of this annual report dates (which end June 30, 2017). However, as the vast portion of the planning for the Conference occurred during the period in question, CAF is including information on the Conference. More than 275 people attended this year's Conference, which presented a unique opportunity for thalassemia patients, family members and friends to hear from some of the finest experts in the thalassemia field on issues of medical significance to the population.

**Distinguished Scholar Award.** CAF makes available its Distinguished Scholar Award to thalassemia patients who are pursuing doctoral studies in biomedical sciences, including medicine, pharmacy, nursing and basic research. (Ph.D., M.D., D.D.S., Pharm.D., D.V.M, etc.) in the United States or abroad. Total annual funding available for the awards is \$20,000. This year, Janelle Trieu, who is pursuing a doctorate in pharmacy was granted the award.

**Patient Incentive Awards.** CAF re-initiated its Patient Incentive Awards program, which had been dormant for several years. These awards are open to U.S. thalassemia patients who are currently pursuing education in a graduate, undergraduate, associate, certificate or vocational level. The purpose of these Awards is to inspire patients to further their education and career goals and to help them live positively with thalassemia. Twenty-one patients received incentive awards totaling \$26,750.

**DC Meeting.** On May 3, 2017, CAF convened a meeting involving representatives from the NHLBI, NIDDK, NICHD, CDC, and HRSA for a day-long meeting in Washington, DC to discuss the current state of thalassemia care and research. This meeting enabled CAF and the various agencies involved to communicate current projects and priorities which will prove helpful in determining goals for coming years.

**#ThrivingWithThal Week.** CAF initiated a new social media campaign, #ThrivingWithThal week, during which thalassemia patients were encouraged to post on Facebook about how they are thriving despite their blood disorder and encouraging others to live their best life.

**Medical Research Fellowships and Grants.** In FY 2017, CAF awarded five new medical research fellowships and renewed funding for an additional three medical research fellowships; total funding equals \$260,000. Funding was awarded in FY2017 for a period beginning July 1, 2017.

Recipients of new medical research fellowships for 2017-2018 include:

**Nikoleta Psatha, PhD**, of University of Washington in Seattle, *Two innovative approaches for genome editing in beta-thalassemia.*

**Antonella Nai, PhD**, of San Raffaele University in Milan, Italy, *Transferrin Receptor 2 : A Novel Potential Therapeutic Target for B-Thalassemia*

**Lei Yu, PhD**, of University of Michigan Medical School, *Development of RN-1 Analogs to Inhibit LSD1 Activity as a Strategy to Treat B-Thalassemia*

**Daniel Lucas, MD, PhD**, of University of Michigan Medical School, *Identification of the cellular targets through which granulocytes drive hematopoietic regeneration after transplant*

**Julia Xu, MD**, of Duke University, *Thalassemia Screening in Myanmar and Lao Migrants in Thailand*

Recipients of renewal medical research fellowships for 2017-2018 include:

**Katie Carlberg, MD**, of the Children's Hospital Oakland, *SNP Discovery and Characterization of the Human Beta-Globin Gene for Non-Invasive Prenatal Testing for Beta-Hemoglobinopathies*

**Merlin Nithya Gnanapragasam, PhD**, of Icahn School of Medicine at Mount Sinai in New York City, *Genome Editing of EKLf Enhancer Elements for Fetal Hemoglobin Induction*

**Karen Finberg, MD**, of Yale Medical School, *The Role of NCOA4 in the Regulation of Hepatic Iron Stores*

## **INCOME AND EXPENSES**

The following is an overview of the Cooley's Anemia Foundation's income and expenses for the fiscal year ended June 30, 2017:

Total Support & Revenue: \$ 2,541,590

Program Expenses:

Research and Grants	\$ 282,781
Public Information	\$ 245,846
Patients Services	\$ 560,024
Community Services	\$ 124,181

Total Program Expenses: \$ **1,212,832**

Management & General Expenses: \$ 180,225

Fundraising Expenses: \$ 298,943

Total Expenses: \$ 1,692,000

End of Year Net Asset Balance: \$ 3,354,908

## **CAF Board of Directors Committee FY 2017**

Anthony J. Viola, *President*

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Ralph Colasanti, *Executive Committee*

Terri DiFilippo, *Executive Committee*

Maria Hadjidemetriou, *Executive Committee*

National Executive Director: Craig Butler

The Cooley's Anemia Foundation is tax-exempt under section 501 (c) (3) of the Internal Revenue Code. Donations are tax-deductible to the extent allowed by law.