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Hadjidemetriou and Butler Discuss Thalassemia and the Cooley's Anemia Foundation

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By Eleni Sakellis

Maria Hadjidemetriou. Photo: Courtesy of Maria Hadjidemetriou

NEW YORK – The Cooley's Anemia Foundation is a national advocacy organization for people living with thalassemia, a genetic disorder originally referred to as 'Mediterranean anemia' as it was first described in people from the Mediterranean region. People of Greek and Italian descent are disproportionately affected as are people from the Middle East and South Asia. The term 'thalassemia' is derived from 'thalassa", the Greek word for sea.

Thalassemia is an inherited blood disorder caused by mutations in the genes responsible for hemoglobin production. There are two main types: alpha thalassemia and beta thalassemia, named after the specific globin chains, affected. The severity of the disorder can vary significantly, depending on the number of affected genes inherited from the parents.

Those with the most severe forms of the disorder require lifelong blood transfusions, often starting in infancy. Iron overload is also associated with thalassemia, requiring a daily drug treatment to attain an appropriate iron balance. Common complications include heart and liver disease, low bone mass, diabetes, growth and development issues, and fertility and pregnancy challenges.

The major form of thalassemia is called Cooley's anemia, named after Dr. Thomas Benton Cooley, the renowned American researcher who discovered the disorder.

Cooley's Anemia Foundation National Executive Director Craig Butler and Maria Hadjidemetriou who is living with thalassemia both graciously spoke with The National Herald about the Foundation and about the disorder which for some patients to survive requires lifelong blood transfusions as often as every two weeks.

TNH: How did you first become involved with the Cooley's Anemia Foundation (CAF)?

Craig Butler: I started as National Communications Director for CAF in 2001 and became National Executive Director in 2016. I feel fortunate to be able to work with an organization that is passionate about its mission and the people it serves.

TNH: How has the Foundation evolved over the years during your tenure?

CB: CAF has since 1954 advocated for the thalassemia community in all areas. Though small in size, CAF has helped promote important advances that have had significant impact upon the community. These include the federal government's creation of the Thalassemia Clinical Research Network, a 10-year project which helped standardize thalassemia treatment in the U.S.; outreach efforts to expand CAF's database of thalassemia patients and to spread awareness of thalassemia among populations most at-risk of thalassemia; and decades-long funding of medical research into thalassemia and related areas.

Craig Butler, National Executive Director of the Cooley's Anemia Foundation. Photo: Courtesy of Cooley's Anemia Foundation

TNH: Are there any recent developments in the treatment of thalassemia?

CB: Yes, there have been tremendous advances in the past two decades. In the past few years, two gene therapy treatments have been approved by the FDA which are enabling many of our patients to at long last become free of the burden of lifelong blood transfusions. Other new treatments help to increase hemoglobin levels so many patients require fewer blood transfusions. Advances in iron monitoring and in iron chelation have helped expand patient life expectancy significantly.

TNH: How can TNH readers become involved in the Foundation and help support the cause?

CB: Donating blood is an excellent way to help everyone with thalassemia and, of course, anyone who needs a blood transfusion at all. There are many ways to help spread awareness of thalassemia or to help raise funds to support our programs for patients, such as by participating in a CAF Care Walk; contact me at cbutler@thalassemia.org if you would like to learn more.

Maria Hadjidemetriou Shares Her Story

TNH: Tell us a bit about your background, where is your family originally from, where did you grow up, and when were you diagnosed with thalassemia?

Maria Hadjidemetriou: I was diagnosed with Thalassemia at 2 years old. I only recently have come to know the story of how I was diagnosed. I wish I would have known this story as a child. We were living in Cyprus at my mother's beautiful village of Kato Drys, a medieval style village with narrow winding cobblestone streets. I was becoming more and more agitated, crying, jaundiced, and my mother took me to the village doctors and they all said the same thing "she is anemic, give her liver to eat." Then a paediatrician came from Ammohostos (present day Famagusta) a relative of my mother's and he said to my mom "just by looking at Maria I can tell you she has Thalassemia and needs blood right away." The next day my mom and I went to the hospital in Ammohostos, this was about 1973/74 before the invasion. We arrived at the hospital and my mom was taken aback by the condition of the hospital. An old woman's voice was heard; she was holding the arm of a soldier and said "έλα έλα και έχω ένα παλικάρι" ("here, here I have a young lad"). The young soldier was a blood donor. The doctor took a blood test to confirm my Thalassemia and then we returned to the village where my mom called my father who was in New York and gave him the news of my fatal disease. Back then Thalassemia was considered a fatal disease. My father (a green beret officer in the Cyprus army) came to Cyprus, packed us up and we returned to our home in Astoria. I was officially diagnosed at New York Hospital, now called Weill Cornell, on 68th Street and York Avenue. There we met several other Greek Cypriot families and we are still friends today.

Maria Hadjidemetriou and her daughter Julia. Photo: Courtesy of Maria Hadjidemetriou

TNH: How has thalassemia affected your life?

MH: As a young girl, the hospital was my second home. It started at around 8 ½ years old where I was not able to hold my hemoglobin. This is because my spleen was very enlarged (6 pounds to be exact). What happens to our organs is they become enlarged, damaged and this leads to organ failure due to the iron overload from being chronically transfused. My spleen was removed and post-splenectomy a hospital was my second home. Every 8-12 weeks I was back in the hospital fighting raging fevers as high as 105 F. On several occasions, my mother was told by doctors "we don't think Maria will make it this time" but my mother never gave up. She prayed to Panagia, Jesus Christ, and St. Irene Chrysovalandou, our church in Astoria and instilled in me The Power of Prayer and to never give up. Till today, my Faith guides me, boldly. Now in my adulthood, I have secondary diseases of Thalassemia and unfortunately, one that has hindered my lifestyle greatly… that is osteoporosis. I have very brittle bones, but I continue to NOT give up and maintain a fitness regimen four times a week. It is easy to give up; that isn't part of my DNA. Being a champion through God's wisdom and the tenacity He has bestowed on me keeps me going.

TNH: How did you first become involved with the Cooley's Anemia Foundation?

MH: A dear friend who passed away who also had Cooley's Anemia, Sophie Soshilos, wanted me to be more involved and I went to a meeting. I felt like it was a second family. I met Bob Ficarra, who is the son of our founder Frank Ficarra, and he was so instrumental bringing me on Board and I joined the Executive Committee, I believe it was 1997. The Cooley's Anemia Foundation is a second family. It hosts a patient/family conference every July and it is a place where patients, parents, doctors, nurses for three days share in their way the journey of our blood disorder. Bob Ficarra is also the Co-Founder of the Thalassaemia International Federation (TIF), which is headquartered in Nicosia, Cyprus. I then became a member of the Board of Directors for TIF in 2007. It is the honor of my life to be serving these boards and be part of the global patient community..

More information is available online: https://thalassemia.org/.

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