

"Life is Precious!"

Patients Tell Why They Stick with Treatments

In August, CAF began a new effort to open up dialogue about the challenges that people with thalassemia face in maintaining their rigorous treatment schedule. Patients and parents of younger patients received a letter asking all those interested to respond to the question, "What is your #1 reason for adhering to your thalassemia treatment?" From the respondents, one name was drawn at random to receive a prize of \$100.

And what are some of the reasons these individuals adhere to their treatment? Some of the responses include:

"My mom!"

"My child – and because breaking the norm is always great!"

"Because it works and that will keep me here for my husband and my family, which is the number one reason."

"Life is precious! As challenging as having thalassemia is, being compliant is a small price to pay for a healthier life. When I first told my husband that I have thalassemia, I told him I could not guarantee a long life; rather, I promised to continue to work hard and do everything I could to stay healthy. So far I have not broken my promise – and never will."

"To stay healthy and be vigilant about (my children's) health."

"My three beautiful children."

"The mere fact of knowing that it would be damaging to skip chelation treatments and blood transfusion. I had to be motivated and follow what I was told to do very strictly."

"To ensure my health and allow me the ability to live out and fulfill my dreams."

CAF thanks all that participated in this first step in our ongoing dialogue about how people deal with the challenges that thalassemia presents.

Celebrities at the Clinic

Marion D. Adinolfi, PhD, MscD, is the author of the soon-to-be-published "Who Said I Can't?: Living with Cooley's Anemia through Love, Loss, The Mafia, Artistic and Academic Success" (Melrose Books). The book discusses Marion's relationship with her younger brother, Ralph Moscato, who was born with thalassemia. Below is an excerpt from one of the chapters:

One Wednesday I brought a portable victrola so that we could listen to some music. The whole mood in the transfusion room began to change; the other children began bringing their toys and asked to be put in wheelchairs so they could sit up instead of lying down for four or five hours. The nurses and doctors were less rigid. They began to realize by bringing playtime into the transfusion room it made a big psychological difference for the children.

Ralph and I became celebrities at the Cooley's anemia clinic. We made a difference. That summer, I became the teacher of our little Wednesday group. It was better for me to be with Ralph while he was being transfused. At home, we prepared poster games for the younger children and those who couldn't use their hands because they were having blood transfusions through veins in their hands. So, I would bring the oaktag posters that Ralph and I had made over to the children who were confined and asked them to point out letters or animals that we drew. All the kids in the clinic and their parents loved me. Ralph and I felt needed and loved. We actually looked forward to seeing each other.

The hospital became our home away from home. There was a very special bond beginning to develop between all of us.

Bank Authors Thalassemia Book

Arthur Bank, Professor Emeritus of Medicine and of Genetics and Development at Columbia University and a longtime leader in thalassemia research, has written a new book, "Turning Blood Red: The Fight for Life in Cooley's Anemia," which is being published by World Scientific Books.

Below, Dr. Bank answers some questions about "Turning Blood Red."

What made you write this book?

I wanted to tell the story of Cooley's anemia from my own point of view since I have been involved with the Cooley's anemia community and research on the disease for my whole professional life. I wanted to share what I knew about the disease with everyone who was interested in reading about it, hopefully in a way that was understandable to both professionals and lay people. I also wanted to tell the story of my research in thalassemia in my own way, in my own words. I have always loved writing, and Cooley's anemia was a subject I thought I could write about from many different points of view: as a scientist, as a physician and as an observer of the disease and its many problems and challenges. I had never had the time to write a book before until I gave up my clinical and administrative responsibilities at Columbia in 2005.

I had originally thought the book would focus mainly on my scientific contributions and the

clinical advances, but my interviews with patients and family members with the disease changed my perspective drastically. I became emotionally overwhelmed by the narratives of the patients and family members I interviewed who shared their experiences with me. I never expected that to happen. It was remarkable to me to see their courage and determination in the face of a serious lifelong disease. I hope I reflect their feelings and their reality in my writing.

What do you want readers to take away from this book?

I hope that patients and family members will learn more about the disease and the research that may eventually lead to a cure. I hope scientists and clinicians who read the book will learn more about the emotional life and trials of patients as well as the research and clinical advances. I also hope that people of all ages who are interested in science and medicine will read the book as the story of a worldwide human genetic disease written from many points of view.

Do you feel that a book such as this can be helpful to the thalassemia community? I hope the book will make people who read it more aware of the disease and more interested in becoming involved with organizations like the CAF, which, in a sense, is the glue that holds the thalassemia community together.