

Summary

Patient Advocacy expert with experience liaising with Pharma and Biotech companies.

As a Patient Advocate and Expert Patient Advisor with global experience, I have built relationships for over two decades serving in the Rare Disease community. I lead with empathy to understand the voice of the patients and their caregivers.

Skills

- Business Planning and Development
 - Fundraising
 - Marketing/Branding
 - Sales
 - Communication Strategy
- Relationship Building
 - Public Speaking
 - Social Media Expertise
 - Divergent Thinking
 - Research on Latest Drug Development

Experience

Expert Patient Advisor/Lead Patient Advocate, 2008 to Present

Maria Hadjidemetriou Consultant – City, STATE

- Consulting with Pharma and BioTech companies as an Expert Patient Advisor for their clinical trials to be more patient centric as well as input on marketing and branding. Provide insight and feedback on clinical trial design and educational support.
- Partnered with brand leadership to influence patient marketing campaigns.
- Assisting biopharma firms in putting together a patient advisory council to capture the patient voice on what their concerns are for Beta Thalassemia.
- Meet with executives in biopharma with the latest innovations in NID (New Investigative Drugs) to explain the Thalassemia patient journey, current treatments, secondary diseases and side effects.
- Staying current on all new therapies currently in clinical trials.
- Wrote essay for Eurordis "Keep On Smiling" featured on their website for Rare Disease Day 2021.
- Published two articles for the peer-to-peer medical journal American Journal of Hematology in 2017 and 2019.
- Wrote and produced short documentary winning two film festival awards "Thalassemia: Life Without Boundaries" now being featured on the Rare Disease Channel. Documentary has also been translated in Arabic, Farsi and Russian.
- Developed agenda for Thalassemia conferences with focus on topics that captures the patients voice and concerns.
- Invited to the Maldives by the Ministry of Health and the Thalassemia Society of Maldives to meet with health officials, doctors and nurses on best practices in maintaining optimal health with Thalassemia.

Executive Board Member, 2005 to Present

Cooleys Anemia Foundation – City, STATE

- Identified philanthropists in the Greek community and developed optimized marketing to engage and interest individuals for annual donations.
- Established goals for soliciting funds i.e. dinner galas; beer tasting; Walkathons; and other creative events.
- Established and maintained positive relationships with government regulators, pharma executives, patients and family members, other area health care providers, physicians and community at large.
- Delivered speeches at annual family/patient medical conference in the forms of sole presenter, Chairperson, panelist and moderator.
- Sourced speakers for annual patient/family medical conference.
- Managed booth exhibits at annual American Society of Hematology (ASH) conference to meet with biopharma executives.
- Presented at the U.S. Food and Drug Administration (FDA) on treatment that was approved in 42 other countries that was not yet approved in the USA. Continued to present at the FDA until 2011 when the treatment was finally approved.

Expert Patient Advisor, 2013 to Present

Thalassemia International Federation – City, STATE

- Created and manage official TIF Instagram account composing content, engage with followers in comments, grow the number of followers, monitor the activities and research health trends for Thalassemia.
- Delivered speeches to groups of people in various healthcare summits and medical conferences addressing Thalassemia, new novel therapies, patient partnership; patient rights; gene therapy; motivational living through healthy eating, exercising and creating an outstanding lifestyle.
- Attended and participated in industry events overseeing exhibit booth and speaking with hematologist and biopharma executives.
- Invited by the World Health Organization to speak in Geneva at the 72nd World Health Alliance on Gene Therapy and at the United Nations on patients rights.
- Invited to speak at the 2013 World Congress Thalassemia meeting in Abu Dhabi with a presentation on "Keeping a Positive Mind with Thalassemia".
- Presented in 2017 in Amman, Jordan holding multiple workshops for our young professionals and mothers/mothers-to-be.
- Invited by Ministries of Health and Patient Organizations to Kuwait and Oman as Delegation Visit addressing patients needs; current treatments; giving best practices on maintaining optimal health with hematologists, cardiologists, nurses, Blood Bank Executives, and Ministries.

Education and Training

Bachelor of Science: Marketing, 06/1994

Fashion Institute of Technology - New York, NY

International Marketing , 08/1993

Instituto Lorenzo De Medici - Florence, Italy

Certificate: Life Science/Genetics , 02/2021

Eurordis Academy - Paris, France

Intense courses on History of Genetic Disease and EU Laws on Rare Diseases.

Certificate: Thalassemia , 10/2020

Thalassemia International Federation - Nicosia, Cyprus

Intense studies on the history of Thalassemia, gene therapy and patient advocacy.