In August of 2007, Marc was diagnosed with mucous membrane pemphigoid (MMP). With several subtypes, pemphigoid and pemphigus are chronic autoimmune disorders characterized by blistering lesions that affect the mucous membranes of the body and the skin which can cause scarring. Progressive scarring leads to serious complications, often affecting the eyes and throat.

Like many others with a rare disease, Marc experienced delays in diagnosis and difficulty finding a physician who could help him navigate the best course of care. Eventually, Marc lost the vision in his left eye from the disease.

In 2018, the FDA granted Priority Review, Breakthrough Therapy Designation, and Orphan Drug Designation for rituximab, which expedite the FDA review processes for innovative treatments for serious unmet medical needs. Rituximab, a B-cell antibody treatment, was approved in June 2018 for adults with moderate to severe pemphigoid vulgaris. Until this approval, all ten types of pemphigus and pemphigoid had been treated “off-label” with a variety of therapies with widely varying degrees of success, as a result, patients faced significant coverage and access challenges. This remains the case today for many pemphigoid and pemphigus patients.

The initial obstacles Marc faced in managing his own care are what ultimately inspired him to help others with the disease. Because of the unique prognoses that come with rare conditions these patients are fraught with crossovers among different specialty providers and contraindications among medications. Marc's advocacy work for pemphigus and pemphigoid patients, and others living with extremely rare conditions, through Haystack Project, has time and again uncovered the immense undertaking involved with accessing treatment. Haystack Project specifically works to evolve health care payment and delivery systems to make innovative quality treatments accessible to the patients they were meant to reach, these same patients who stand to benefit most from the work of FDA's expedited programs.

Now one of the handful of ultra-rare conditions with an FDA-approved treatment, people living with pemphigoid and pemphigus have hope for further progress towards additional treatments with improved results. The important work of Marc and many others will persist in elevating the patient voice in support of continued investment in R&D and value discussions that support effective treatment solutions for diseases with unmet need.