

# The impact of patient advocacy on healthcare

Bringing a whole new meaning to personalized medicine

by Susan Cuzzo

**Kathy Giusti, CEO of the Multiple Myeloma Research Foundation (MMRF). Marilyn Geller, CEO of the Celiac Disease Foundation (CDF). Wendy S. White, founder and president of Siren Interactive, an advertising agency focused solely on rare disease. What do these women have in common? They are leading organizations that are driving innovation, awareness and research in diseases once relatively unknown or incurable—and they're all coming at it from a personal connection.**

## A pioneer of patient advocacy

In 1996, when Kathy Giusti, then a 37-year-old executive director at G.D. Searle (now part of Pfizer), was diagnosed with multiple myeloma and told her cancer had a zero percent cure rate, personalized medicine was not a commonly talked about theme in healthcare and the idea of pharmaceutical companies working directly with patients—or even marketing directly to them—was in its infancy.

But being a savvy business leader and a pharma insider, former HBA Woman of the Year (WOTY) Giusti, along with her twin sister, a corporate attorney, recognized that they could—in fact had to—make a big and rapid impact. They founded the MMRF, formed partnerships with corporations like Searle, Time Inc. and Grey Healthcare, and within 16 months, had raised nearly a million dollars for research.

Fifteen years later, the MMRF has raised \$225 million, sequenced the myeloma genome, opened 46 trials of 23 drugs and supported the FDA approval of six new treatments. The result? They've helped to more than double the life span of multiple myeloma patients. And, they've founded CoMMpass<sup>SM</sup> (Relating Clinical Outcomes in MM to Personal Assessment of Genetic Profile), the first study of its kind in multiple myeloma that will collect and analyze tissue samples and genetic information from

approximately 1,000 multiple myeloma patients—and match it with longitudinal clinical data—over the next 8-10 years. Ultimately, the data, which will be placed into the public domain for researchers worldwide to access, will help to speed the progression to targeted treatment approaches. The study, which includes an unprecedented collaboration with the US Department of Veterans Affairs, funding by several pharmaceutical companies and participation by more than 50 cancer centers across the country, marks an incredible coming together of a non-profit association with government, corporations and clinical centers to drive innovation.



What's more is that Giusti, and others like her, have inspired millions of patients with rare or difficult-to-cure diseases to take matters into their own hands—bringing a whole new meaning to the term “personalized medicine.” For them, it's all personal, and it's that determination to cure themselves, their parents and siblings, children and friends that drives them to demand awareness, attention and research.

“Today more than ever, patients have the power to play a major role in their treatment and care,” says Giusti. “By donating tissue and sharing their data through MMRF initiatives, patients are directly contributing to the advancement of precision-based medicines from which they themselves will benefit.”

## An agency leader dedicated to rare diseases

Wendy White, founder and president of Siren Interactive and board member of the executive committee for the HBA, knows all too well the important role that patient advocacy plays in both rare disease diagnosis and bringing orphan drugs to market. Her daughter, born in 2001 with a rare disorder, was diagnosed as a direct result of White's becoming an empowered caregiver through access to online information.

White turned her experience and passion into Siren Interactive, where she leads an agency team that works to make a positive difference in the lives of rare disease patients, caregivers and physicians through relationship marketing. She has witnessed first-hand the win-win results that come from the collaboration of industry and non-profit organizations to advance the treatment of patients with rare diseases.



“Patient advocacy groups frequently lead the way, driving the science and working with academics getting drugs through clinical trials and sometimes actually funding pharma,” says White, referencing her friend Pat Furlong, founding president and CEO of Parent Project Muscular Dystrophy (PPMD). Furlong lost two sons to Duchenne muscular dystrophy, which is the most common fatal genetic disorder diagnosed in childhood, affecting approximately 1 in every 3,500 live male births (about 20,000 new cases each year). PPMD has funded research conducted by independent researchers as well as major pharmaceutical companies to help develop much needed therapies for Duchenne.

“In the rare disease space, advocacy and industry work collaboratively and differently than in the traditional model and this is probably going to happen more in the future as people are forced into taking healthcare into their own hands,” says White, noting the MMRF’s CoMMpass study as a key example. She also explains that another model often seen in rare disease, where there may be a more fractured advocacy landscape, is when a drug therapy or brand can actually serve as a consolidator to bring multiple advocacy groups for a given disease together. “Regardless of the model, it is really all about the common denominator—patient outcomes,” she says.

### **A mother raising awareness of a serious disease**



In addition to research and treatment, patient advocates and their philanthropic organizations are also driving awareness and understanding of previously overlooked diseases.

Marilyn Geller’s journey to becoming CEO of the CDF began when her son Henry was finally diagnosed with celiac disease after suffering from

chronic sinusitis and severe stomachaches for the first 14 years of his life. After being seen by a variety of specialists, it was recommended that Henry have sinus surgery to address the post-nasal drip that was presumably causing his terrible stomachaches. Uncertain about the surgery, Geller asked for every possible test to be done first. It was a simple \$29 blood test that led to a celiac disease diagnosis—a test that should have been ordered years before.

Like any good parent, Geller went on to educate herself about the disease, eventually leading to her involvement in the CDF, where she now works to educate others. “Raising awareness is critical,” she notes, as an estimated 2.5 million of the 3 million Americans with celiac disease remain undiagnosed.

In addition to education and outreach, the CDF is pushing for legislation requiring accurate labeling of all food and medications to give people the information they need to avoid gluten. The organization also actively raises funds to support research and advocates for continued federal funding to further the understanding of celiac disease. According to Geller, relationships with pharmaceutical and biotechnology companies help the CDF execute its myriad programs. For example, partnerships with ALBA Therapeutics, Alvine Pharmaceuticals, Bioline Rx and ImmusanT helped to make the 2013 National Education Conference and Gluten-free EXPO—the nation’s leading patient education and support conference for celiac disease and gluten sensitivity—a reality.

### **Taking matters into your own hands**

We hope these women have inspired you to make medicine personal. White offers this advice for getting involved in a partnership to drive awareness, research and innovation in medicine: Have an idea, start a dialog and don’t be afraid to follow your passion. The possibilities are greater than ever before as the borders between advocacy and industry continue to become more fluid. “If you want to make a difference, the opportunities are there for you to follow your passion,” says White. “The concrete steps are to be brave and lean in and make a suggestion about what may be best for patient outcomes and think about it more broadly than your own job description.”

### **Tell us how your organization works with non-profits to further healthcare causes**

Share your experiences partnering with patient advocacy or philanthropic organizations to further healthcare causes. Send an email to [cmeerschaert@hbanet.org](mailto:cmeerschaert@hbanet.org) or visit our blog at <http://hbanet.wordpress.com/>.