

# The Multiple Myeloma Research Foundation

## An interview with Kathy Giusti



**HONI:** You and your twin sister, Karen Andrews, founded the Multiple Myeloma Research Foundation (MMRF) in 1998 after you were diagnosed with multiple myeloma. Besides the obvious reason, what inspired you to do this?

**Giusti:** When I was diagnosed in 1996, I was surprised by how dismal the [survival] statistics were. There was no cure, [it was] 100% fatal, and [led to] an average life span of about three years. But what was probably the most devastating to me, working in the [pharmaceutical] industry like I did, was when I looked at all the resources I knew to see what new drug compounds were being developed. In the field of multiple myeloma, there were absolutely none. There was not one compound to be found in early development—Phase 1 or Phase 2—anywhere in multiple myeloma. I honestly remember calling my sister and saying, “I’m a fighter, and I’ll give it my best shot, but I don’t know how I am going to beat this one.” There was absolutely no research funding or progress being made. So I knew somebody had to do something.

**HONI:** According to your website, [www.multiplemyeloma.org](http://www.multiplemyeloma.org), the MMRF has raised more than \$15 million, and about 93% has been directed to research. How are you able to funnel so much of the donations into research?

**Giusti:** We are an incredibly lean organization. Part of our culture is to hire people who are extremely dedicated, who will work seven days a week, and tirelessly for the cause. So, with our staffing, it is because we work so hard.



*Ms. Giusti is cofounder and president of the Multiple Myeloma Research Foundation (MMRF). Prior to founding the MMRF, she worked in the pharmaceutical industry at Merck and G.D Searle, which is now part of Pfizer.*

In addition, we also use volunteers really well. To give you an example, a significant portion of our funding comes from events that we do. All of our events are supported by volunteers. When we do races in different cities, we have committees of volunteers in those cities that oversee those races for us and do a lot of the legwork on them. When we host a corporate event, we typically have anywhere from 5 to 10 dinner chairs that all volunteer and reach out to different corporations in their city. We have a whole team of volunteers that actually come into our office to do specific administrative work. We have a volunteer that literally oversees our entire Advocacy Day.

So our strength is a hard-working staff in combination with significant volunteerism.

**HONI:** Clinical trials seem to be an important focus on the MMRF website, particularly the Clinical Trials Monitor tool. Why are clinical trials so vital?

**Giusti:** In multiple myeloma, the way it works right now, there are a number of new treatments that are emerging. Velcade is one. Revimid is one. Trisenox is one. Think of this disease. For decades, we haven't had new treatments. So, first of all, trying to educate patients and community oncologists on these new treatments as opposed to stem cell transplantation has been a big undertaking. If you are a myeloma patient and you are only going to live for potentially three or four years, you need access to where these new therapies are available, and right now, you can only get them in clinical trials.

Let's, say that you are a patient, and you've had a transplant and now relapsed, and you are looking for the next option available to you. Well, if you want Velcade, Revimid, or Trisenox, you've got to find it in a trial. That's a lot to ask the patients to do, so that's why we developed [the Clinical Trials Monitor] area of our website, which focuses just on clinical trials.

To put it in perspective, we have had 14,000 visitors through that section of our website looking for clinical trials. I don't know of any other organization that has taken it upon itself to do that. Our program director and webmaster have dedicated literally hours and hours to updating the information on that part of the site.

It especially helps with the single-institution trials. For example, there is a new trial combining two different drugs at a hospital in Arkansas, and it's not available anywhere else. Or Dana-Farber has a really interesting dendritic-cell vaccine trial. We have to do the pharmaceutical trials, the single-institution trials, and update every IRB [Institutional Review Board] as it is approved. That's a huge undertaking, but we feel that it is critically important for the community oncologist as well as the patients, to know where the trials are.

**HON:** Do you see the community oncologist as one of your target audiences?

**Giusti:** That's who we really try to reach out to. Our attitude is that the community oncologists are trying to stay up to speed on so many different types of cancers, and they may have 5 or 10 myeloma patients, yet they need to know where to place these people so they can get the best treatment.

We try to do everything we can to proactively educate

them. That's why we are masters of collecting email, and we literally email the community oncologists CME [continuing medical education] material. For example, Velcade is at the [U.S. Food and Drug Administration] awaiting approval. We have a CME program done on that product. It's ready to go the day it gets approved. [Editor's Note: Velcade was approved soon after this interview, see *Clinical News*, p. 11.] Millennium is just starting their sales force, so it's really important that we be able to teach the community oncologists how to dose the drug, what toxicities they can expect, and how to manage that. We do a lot of CME for the community oncologists.

We're a very unusual foundation that way. Probably because of my background in the pharmaceutical industry, I am very comfortable on the research side. I'm also very comfortable on the medical education side because that is what you do when you work in a pharmaceutical company. You do a lot of medical education.

**HONI:** We are also very interested in your advocacy efforts. How involved have you been in the efforts to get oral drugs covered, including the Access to Cancer Therapies Act recently re-introduced to Congress?

## ADVOCACY

**Giusti:** Very involved. Our advocacy efforts are based on the needs of the community. A couple of years ago, our focus was on getting stem cell transplants covered by Medicare, and we actually oversaw that whole project.

Now we have moved on to oral drug coverage, primarily because Thalomid is an oral drug as is its next generation, Revimid. It's so important that we get this covered.

We'll be hosting an Advocacy Day, which we do every year in Washington, D.C., on June 17 and 18, and our focus for Advocacy Day is oral drug coverage. We will have 100 advocates there for myeloma, as many as for lymphoma or other major cancers. Yet myeloma patients represent only about 1% of all cancer patients. The myeloma community really partners with us and believes in what we do, and they want to support us. They go to Washington, and we have a great turnout. We really make some good headway.

I think it also helps that [former Congresswoman and vice presidential candidate] Geraldine Ferraro and Senator Kay Bailey Hutchinson [R-Texas] have been affected by the disease. For Advocacy Day this year, we are being joined by Andy Von Eschenbach, the head of the NCI [National Cancer Institute], which shows his support for the myeloma community.

One of the goals of Advocacy Day is to get more research funding for the blood cancers. The truth is that we, a private organization, are the major funder for myeloma research. This year alone we will give out \$5 million. Our discussions with the NCI and the government are about creating a huge groundswell of ideas, but we need the NCI to partner with us.

The worst thing that would happen is that we create this huge groundswell of ideas, but then we can't get them moved into Phase 3 trials because the industry is not picking it up or the NCI is not picking it up. Our attitude is—let us do the early research. Let us act like a venture capital company, but please work with us, and then let's take these grant ideas and move them outward.

I love Velcade as an example of that. We started working with Millennium years ago, actually in 2001, when we heard that they had PS-341, which was looking promising. They asked to join us at a research roundtable that we were doing. And that was the first place that Velcade was presented to the myeloma community, at our research roundtable. At that same meeting, they sat with these lead clinicians and developed

their Phase 2 protocols. Just giving them access to meetings that we were already holding gave them a jump-start.

Then, we funded \$2 million in Velcade research, including a \$1.5 million program grant around their Phase 2 trial. Then as you see on the Clinical Trials Monitor, we became a lead referral source to their clinical trials; they accrued patients faster because we could easily tell all the patients, where the trial was open, and where you need to go if you relapse. We were able to share the criteria with them, and now here we are working with them to communicate CME information on this drug to the community oncologists. So it shows you how we work early on in funding drug development, and then we work all the way through in terms of accruing patients for clinical trials faster, and we also help to educate the myeloma community. That's what we take the most pride in.

**HONI:** It sounds like an outstanding program.

**Giusti:** It is, and we try to do the exact same thing with other drugs like Revimid. We have seen that these compounds are looking very promising. You do want to move them because we have a sense of urgency. These patients are dying. They don't have the resources. We take all these phone calls from patients, and we really do empathize with them.

In the meantime, we are probably funding 10 other compounds in preclinical stages with our research grants. So while we focus on what's in Phase 3 trials now and getting those approved, it certainly doesn't stop us from some very early preclinical funding for compounds that look promising.

**HONI:** This information will be a great resource about advocacy for our readers.

**Giusti:** I think it gives you some perspective. I always tell Andy Von Eschenbach and others that I work with (I'm on the National Cancer Policy Board, too) that every advocacy organization is working on something different, and I think it's so complicated to get your hands around all of us. Some are so beautifully run, and some with great intentions aren't that well run. I think it's really hard for the community oncologists to sort through it and decide who can really help them improve patient care. They don't have time to sit there and try and find every organization that could be of service to them. It's a very tricky thing. ■

*For more information, call MMRF at 203.972.1250, email [themmrif@mmrf.org](mailto:themmrif@mmrf.org), or visit [www.multiplemyeloma.org](http://www.multiplemyeloma.org).*