

Foundation Drives Research Agenda for Multiple Myeloma

When the National Cancer Institute announced its Cancer Genome Atlas project in December, the Multiple Myeloma Research Foundation's leaders already knew that their disease would be far down its list of priorities. After all, the relatively rare cancer accounts for only 1% of cancer diagnoses, with about 16,000 new cases each year.

So the Connecticut-based MMRF isn't waiting for the federal agencies. It is ahead of the curve, funding its own \$6 million, 3-year initiative to map the multiple myeloma genome. The foundation is setting its own agenda, having already created a consortium of 11 collaborating institutions called the Multiple Myeloma Research Consortium, including powerhouse research centers like the Dana-Farber Cancer Institute, the Mayo Clinic, and the University of Chicago. They also created a tissue bank with hundreds of bone marrow and matching peripheral blood samples.

"We were finding we weren't making progress as quickly as we wanted to and that we really did need to take a more proactive stance as opposed to just funding the best (grant proposals) that we received," said Anne Quinn Young, M.P.H., MMRF program director.

The foundation decided that it could serve best as a "catalyst," in the words of MMRF President Nancy Sumberaz, R.Ph. It brought together possible competing interests and hammered out details of intellectual property rights, publication priority, and other issues that can hamper effective collaboration.

The resulting project is set up not as a grant but as a contract between the research consortium, the Translational Genomics Research Institute (TGen), and the Broad Institute of MIT and Harvard. The group will study multiple myeloma patients samples that they hope will help identify new therapeutic targets and, in turn, drive patient selection for clinical trials based on the molecular characteristics of the patients' disease. The data will be placed in the public domain in real time, often even prepublication, and analyzed data sets will be added to the raw data as work is completed.

"It's a completely new model," Sumberaz said. "Any time you have a new kind of way of doing business, you [can] get a group of people who say 'that can't possibly ever work,' which, for me, is a source of inspiration."

—Karyn Hede

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