

Multiple Myeloma Research Foundation



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Mission

The Multiple Myeloma Research Foundation (MMRF) pursues innovative means that accelerate the development of next-generation multiple myeloma treatments in order to extend the lives of patients and lead to a cure.

Strategy/Approach

MMRF provides end-to-end solutions for accelerating drug discovery and development. It employs four key initiatives in an effort to improve and speed medical research aimed at bridging drug discovery gaps through innovative research, sharing knowledge, and developing new business solutions to inject speed and efficiency into the drug development pipeline.

- **Multiple Myeloma Research Consortium (MMRC)** – Founded by Kathy Giusti in 2004 and currently comprised of 16 leading research centers across North America, the MMRC was the first clinical network that brought together leading academic centers solely dedicated to Phase I and Phase II clinical trials. It has set into motion more than 30 clinical trials and more than 20 new drugs and drug combinations, providing more than 1,000 multiple myeloma patients with treatment.
- **MMRC Tissue Bank** – Launched with the MMRC in 2004, this is the first and largest multicenter, Good Laboratory Practices-quality biobank that integrates patient tissue samples with corresponding laboratory and clinical data. It allows for the conduct of cutting-edge genomics studies as well as correlative science studies associated with MMRC clinical trials.
- **Multiple Myeloma Genomics Initiative (MMGI)** – MMRC aligned its strategy with the Broad Institute and Translational Genomics Research Institute to launch MMGI in 2006. It is a comprehensive genome-mapping methodology with the goal of uncovering the genes and molecular pathways involved in myeloma, and identifying new targetable, vulnerable, and druggable aspects of the disease. As of 2009, it had mapped the genomes of 100 patients. All research is channeled into a public portal prior to publication.
- **Multiple Myeloma Personalized Medicine Initiative** – Founded in 2011, this program aims to match patients with treatments customized to their individual molecular profiles. The CoMMpass Study, which focuses on disease progression and response to treatment based on patients' genomic or molecular profiles, is the basis of this initiative. Data from CoMMpass will also be placed into a public portal prior to publication. The CoMMpass study will involve 1000 patients over 10 years, with molecular

analysis of each patient, to better tailor treatment to each patient's biological makeup.

Research Portfolio

To date, MMRF has awarded more than 250 research grants at 130 institutions around the world. It has also supported 11 biotech and pharmaceutical companies through the Biotech Investment Awards and Clinical Fund.

The foundation's current portfolio of **awards** includes:

- **Senior Research Award** – For investigators with more than five years of experience in blood cancer research
 - *Up to \$100,000/year for two years*
- **Research Fellow Award** – For investigators with fewer than five years of experience, and working under a research sponsor
 - *\$75,000/year for one year*
- **Biotech Investment Award** – To provide resources for biotechnology and pharmaceutical companies to test multiple myeloma treatments and encourage collaboration with academic experts
 - *Up to \$1 million per award*

Partnership Practices

MMRF engages in corporate and academic alliances. MMRF's consortium brings together the foremost myeloma researchers.

MMRF partners with biotechnology and pharmaceutical companies through its Biotech Investment Awards, of which they have awarded 11 awards for a total of \$11 million since 2007. Examples include:

- The MMRC and **Millennium** (the Takeda Oncology Company) have worked closely for a number of years, launching 18 trials with Millennium's compounds through the MMRC's clinical network.
- Partnered with **Onyx Pharmaceuticals** to establish the Carfilzomib Myeloma Access Program (C-MAP), making carfilzomib available to patients before general availability.
- Awarded \$1 million each to **Constellation Pharmaceuticals, Inc., Epizyme, Inc., and Karyopharm Therapeutics, Inc.**
- Thanks to investments in **Astex's AT7519** and **Intellikine's INK128**, these two drugs are now being studied through MMRC.

Financials

MMRF is a 501(c)(3) charitable organization. Ninety percent of the MMRF total budget goes directly to research and related

programming. The most recent financial information available is from 2012.¹

- **Director of Translational Research:** Joan Levy, PhD, levyj@themmrf.org

Year ending 12/31/2012:

- Revenue: \$29,482,391
- Assets: \$24,122,682
- Medical Research Grants: \$7,789,193
- Gifts received: \$26,496,124
- Expenditures: \$28,316,239

Key Accomplishments

- Nearly 90% of the MMRF total budget goes directly to research and related programming, consistently earning MMRF top rankings from the nation's leading charity evaluators.
- Funded over 250 researchers at over 130 institutions worldwide through Senior Research and MMRF Fellows Awards, 11 biotech and pharmaceutical companies through Biotech Investment Awards and Clinical Fund
- Set into motion 45 groundbreaking clinical trials and more than 20 new drugs and drug combinations with its clinical network. Data show that trials conducted through MMRC were opened an average of 60 percent faster than the industry standard.
- First to map the myeloma genome in 2009.
- Was instrumental in the launch of six new FDA-approved multiple myeloma treatments (Velcade®, Revlimid®, Thalomid®, Doxil®, Kyprolis™, and Pomalyst®) that not only doubled life expectancy among some patients but also are being tested or used in more than 30 other cancers.
- Earned Charity Navigator's highest rating – four stars – for nine consecutive years.
- In 2012, the MMRC and Millennium advanced the groundbreaking CoMMpass (Relating Clinical Outcomes in MM to Personal Assessment of Genetic Profile) study, a landmark initiative to transform the discovery and development of individualized treatments for the disease in which 1,000 patients and 50 sites will participate.
- Kathy Giusti, founder and CEO, was honored at the White House as a Champion of change for promoting open scientific data and publications to improve the world. She was awarded the 2013 Leadership in Personalized Medicine Award from the Personalized Medicine Coalition.

Leadership

MMRF is governed by a Board of Directors and relies on its Leadership Council and Technology Board for counsel on related matters and policies.

- **Founder and CEO:** Kathy Giusti, giustik@themmrf.org
- **President:** Walter M. Capone, caponew@themmrf.org

¹ Information obtained from MMRF Financial Reports, <http://www.themmrf.org/about-the-mmr/financial-reports/>, March 2014 .