1,000th patient joins landmark MMRF CoMMpass Study

1,000 THANK YOUS

Collaboration between industry and researcher

The most comprehensive database in myeloma

Gaining insights for personalized treatments for patients

INSIDE:
- Precision Medicine — The Time Is Now
- All About Immunotherapy
- MMRF CoMMpass Study
Dear Friends,

In September of this year, we reached a critical milestone in the landmark MMRF CoMMpass Study™ when the thousandth multiple myeloma patient joined. The ground-breaking project is the largest long-term genomic study ever conducted in myeloma. We extend our heartfelt gratitude to each patient as their continued participation will help us decode this devastating disease and usher in a new era of more precise and individualized treatments, leading to cures.

As with other such visionary, pioneering initiatives, quite a few people told us we could never reach this milestone. But by seeking out the best, forward thinking partners, working together to remove obstacles, and delivering new ways of accelerating the process of drug development, the MMRF has achieved an unprecedented number of advances and treatments in the battle against multiple myeloma.

The realization of this ambitious initiative would never have been possible without the participation of our 1,000 patients, researchers from more than 100 collaborating centers, our pharmaceutical company and research institution partners, and supporters like you who directly fund our efforts.

We have arrived at Phase 1 of the CoMMpass Study, and are now launching Phase 2 to follow all patients for at least five more years. And in parallel, we are driving more new, promising drug programs into the clinic than ever before. We thank our sponsors for their support of Accelerator, The Magazine of the Multiple Myeloma Research Foundation.

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On behalf of all of us at the MMRF, we thank you for your continuing support.

Wishing you and your family a happy year-end to 2015 and a healthy and prosperous 2016.

Walter M. Capone
President and
Chief Executive Officer, MMRF
Multiple myeloma, we now know, is not one disease; it’s many subtypes, each one driven by mutated genes and other abnormalities that affect everything from how aggressive the disease is to how likely a treatment is expected to work. Precisely selecting the best treatment based on a person’s subtype rather than a one-size-fits-all-approach has the power to dramatically transform the way we treat cancer. In some cancers, this approach — known as precision medicine or personalized medicine — already has.

Lung cancer patients with tumors that have a defective ALK gene, for example, live more than twice as long when treated with a drug called Xalkori, which zeroes in on the abnormal gene to block its cancer-causing action. The same goes for a subtype of breast cancer patients whose tumors overexpress a protein called HER2; when these women, known to have HER2+ breast cancer, are treated with Herceptin, the drug stops cancer in its tracks.

The Promise of the Personal

Though today these remarkable successes are only seen in some cancers and only for some people with those cancers, we at the MMRF believe a precision medicine approach to cancer is indeed possible for patients with multiple myeloma and many other cancers. That’s why we have made precision medicine our top priority.

At the heart of our Precision Medicine Initiative is the MMRF CoMMpass Study, which includes the collection, aggregation and analysis of genomic and clinical data from 1,000 patients to gain deeper insights into the disease’s biology and lead to hypotheses for more precise clinical trials. We aim to do the same for patients who carry additional mutations and other abnormalities, such as FGFR3 and p53. As we begin to treat patients by their subtype, we will dramatically extend lives and find cures.

Entering a New Era

For the first time ever, this kind of breakthrough science can happen rapidly. Why?

We are at the center of the perfect convergence of massive technological leaps. Genome sequencing, for one, has seen costs plunge from $3 billion to under $3,000, and time collapse from a decade to a few days. Bioinformatics advances now allow us to collaboratively analyze floods of sequencing data — and to do so increasingly in the cloud. And, third, the digitization of health information makes it easier than ever for patients to be a vital part of the process. In fact, studies like CoMMpass are only possible when patients are willing to bank their tissue, undergo genomic testing, and share their health and personal data. Sharing our data — particularly sequencing data, which provides unprecedented insight into the biological underpinnings of health and disease — not only helps us learn about our disease and improve our treatment options, but contributes to knowledge that is vital to the development of new treatments that extend lives and lead to cures.

My sister and I were recently featured in an article in the Wall Street Journal on DNA sequencing. Our family took part in a study to have our complete DNA sequenced in the hopes not only of learning more about our diseases and our family’s risk of developing cancer, but to contribute to scientists’ understanding of cancer for future generations. We haven’t received our data yet, but when we do, the first thing we will do is share it.

Kathy with her twin sister, Karen
A short course in immunotherapy

How the immune system can be trained to attack cancer
the way it does other foreign invaders

Our immune system is constantly on guard for abnormal cells
that, left unchecked, can form into a benign or malignant cancer. This is
called immune surveillance, and is part of everyone’s innate immunity. It
helps prevent us from getting cancer. It’s increasingly evident, however,
that it also can play a critical role in treating many forms of cancer,
including multiple myeloma. Immunotherapy, a promising area of
precision medicine, is incredibly exciting, but also very complicated.
To understand why, it helps to know the basics.

The immune system has a remarkable ability to locate, recognize
and attack proteins and many foreign invaders including viruses
and bacteria that do our body harm. Unfortunately, specific to
cancer cells, they can be very good at evading and outwitting it. So
researchers are looking for ways to give it an upper hand.

The immune system’s “tag team”

There are two parts to our immune system that work hand-in-hand: innate and adaptive.

The innate mechanisms are the “first responders” – cells that
circle the body in search of trouble and react immediately,
shepherding the rest of the immune system to respond. Natural killer
cells (NK cells) are an example of such a cell, and are of keen interest
to researchers for their potential to recognize and kill cancer cells.

The adaptive mechanisms include highly specialized cells such as T-cells
and B-cells that eliminate or prevent the growth of specific disease-causing
pathogens. The adaptive immune system has the ability to clone its fighter
cells to, in essence, mount an “army” against an invader. It also has “immunological
memory” – meaning the ability to remember and thwart future invaders.

How monoclonal antibody drugs work

Imagine if it were possible for a molecule
to be created that could essentially
mimic our body’s natural antibodies,
locating cancer cells and putting a
bullseye on their backs so that the
immune system can attack and kill them.

That’s the idea behind monoclonal antibodies (mAbs). These are large
proteins that are engineered in the lab to attach to specific proteins on the surface
of the cancer cell to make it more visible
to the immune system. Once attached,
the cancer cell can be killed either by a
direct effect, such as a toxin or radioactive
isotope which is also carried by the mAb,
or by recruiting NK cells to stick to them,
thus activating other elements of the
immune system to respond.

The drug elotuzumab, which has
completed phase 3 clinical trials, and
is being evaluated by the FDA for
potential approval, is one such mAb. It
binds the protein SLAMF7 (also known
as CS-1), which is present on myeloma
cells, but also NK cells. Therefore, it
flags the tumor cells and activates
the “foot soldier” cells that can kill the
tumor cells. The MMRF helped drive
participation in this drug’s early clinical
trials, which built the foundation of
proof necessary to get to phase 3 trials,
and also invested in compounds that led
to its development.

The potential for elotuzumab to
provide long-term sustained remission
looks encouraging, particularly when
used in combination with other drugs
(such as Revlimid).

Another mAb in consideration for FDA
approval is daratumumab, and other
monoclonal antibodies are in clinical
development for myeloma as well.
We’ve only just scratched the surface.

Re-educating dendritic cells with vaccines

Though myeloma cells have the
antigens present to be recognized
by the immune system, the cells are
able to “hide,” or be surrounded by
inhibitory cells, and actively shut down
potentially reactive T-cells.

The idea behind cancer vaccines is to
create a new “education system” for
the T-cells so that they recognize the
myeloma cells as foreign and go after
them without restraint. One of the
key players in this strategy is called
dendritic cells. These play an important
role in bridging innate immune responses
with adaptive responses.

One approach is to inject patient-derived
tumor cells fused with their own dendritic
cells or those generated outside the body.
This in essence “teaches” the patient’s
immune system to seek and destroy the
specific myeloma cells the same way it
would any other invader.

A national study supported by the MMRF,
which took patients going through a
transplant to see how a vaccine such as
this might be an important component
in stimulating the immune system and
potentially targeting leftover disease
after the transplant, is showing potential.

In yet another approach, the DNA
of myeloma cells of an individual
patient are sequenced and compared
to normal DNA sequences from the
same patient to identify mutations.
Producing synthetic versions of the
proteins with the mutation in them can
form the basis of a vaccine that will
stimulate the mutation-specific T-cells
to identify and kill them. Clinical trials
for vaccine strategies such as these are
going on throughout the country.

The potential for immunotherapy and
other precise and highly personalized
approaches to cancer treatment has
never been more profound and have the
potential to extend lives and find cures.
Minimal Residual Disease (MRD) gets its due

For patients once thought to have achieved a complete response following treatment, scientists have always known that small amounts of cancer cells can remain. This is known as minimal residual disease (MRD) and its presence appears to increase the risk of relapse among patients. Detecting MRD could help doctors provide more effective care.

MRD could also help measure the efficacy of drugs in clinical trials faster and more accurately than current endpoints, such as overall response rate and progression-free survival. This could help speed drug development and approval.

The challenge? It is currently uncertain what level of detection of MRD is sufficient to appropriately estimate the risk of disease progression, and clinical trials are needed to further evaluate the various methods. The MMRF is collaborating with researchers to compare two of the new technologies in the INSIDE MM-1 study.

With so much interest in and need for an accurate and uniform way to measure MRD, on July 10, the MMRF helped host the ‘Advances in Minimal Residual Disease Testing in Multiple Myeloma’ meeting at Memorial Sloan Kettering Cancer Center, Professor of Medicine at the Weill Cornell Medical College; and Peter Brodhead, Chief, CME Office, Office of Physician-in-Chief, Memorial Sloan Kettering Cancer Center.

During the first portion of this meeting, participants reviewed the advances and new data from ongoing trials that have emerged in the 12 months since the last meeting in the field of MRD testing for myeloma patients.

Next, a debate session tackled the following questions:

- Should MRD be an endpoint for all clinical trials for myeloma?
- Is MRD ready for prime time in standard clinical care?
- Is MRD ready as a regulatory endpoint in myeloma?

During the last portion of the meeting, participants worked on formulating a consensus around uniform MRD testing criteria and laying a path for the use of MRD in clinical trials as well as in routine care. The day closed with a live webcast that recapped the deliberations and recommendations from the assembled participants.

Watch “Live”

A recording of the live webcast from the "Advances in Minimal Residual Disease Testing in Myeloma Meeting" recaps deliberations and recommendations.

Watch at themmrf.org/mrd

The INSIDE MM-1 study

The MMRF together with research partners are conducting a study to compare two methods of measuring MRD.

Flow cytometry measures the number and characteristics of cells taken from a bone marrow aspirate or a blood sample.

Molecular tests evaluate alterations specific to the DNA of cancer cells and can detect very low numbers of cells. This is also known as next-generation sequencing (NGS).

Patients will be monitored for MRD using both methods at regular intervals from initial diagnosis for up to five years after initial treatment. The goal of the study is to rapidly and systematically assess the accuracy, reliability and predictiveness of the two monitoring methods.

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To date in 2015, the MMRC has activated 4 clinical trials, bringing our portfolio total to 18 available for patient enrollment. Overall, the MMRC has been involved in over 60 unique clinical trials, with many more in the start-up phase, which we will report on in future issues of Accelerator.

Importantly, all these studies align with our core research priorities: immunotherapies and antibodies, and novel agents and mechanisms. Historically, a majority of MMRC trials have been focused on relapsed/refractory disease. In the last two years a number of MMRC trials have been evaluating investigational agents in the upfront setting and in post-autologous stem cell transplant. This year and going forward, a major focus of the MMRC is to expand into different myeloma-related patient populations and open trials for conditions associated with advanced disease conditions.

One of the areas that the MMRC will be focusing on is Smoldering Multiple Myeloma (SMM). SMM is one of the earliest forms of multiple myeloma when malignant myeloma cells can be detected in the bone marrow but patients are not showing overt signs of the disease such as anemia, renal insufficiency and bone lesions. This is an area of interest by many experts in the field, as it is believed that early therapeutic interventions in patients with SMM will prevent/delay progression to overt MM. In the previous issue of Accelerator we described the MMRC’s first trial to evaluate the effects of an agent in patients with SMM. The trial sponsored by Janssen Biotech, Inc. is investigating the effects of daratumumab, an anti-CD38 antibody in SMM patients. This drug is in late stage clinical development for multiple myeloma and works by binding to a protein (SLAMF7) on the surface of myeloma cells which signal the immune cells to destroy the tumor cells. In addition, elotuzumab can directly activate special immune cells called Natural Killer cells that can destroy tumor cells. Based on the activity of lenalidomide and dexamethasone in patients with high risk SMM and on the safety and activity profile of elotuzumab and lenalidomide in patients with relapsed MM, she will examine the activity of elotuzumab, lenalidomide and dexamethasone in patients with high risk SMM. The goal of the study will be to identify the role of early intervention with this novel drug combination on prevention of progression in patients with high-risk SMM to active myeloma.

This study is currently open at DFCI and a number of sites in Boston and Levine Cancer Center should be opened shortly.

Additional focus of the MMRC going forward is to explore conditions related to advanced disease. This includes extramedullary disease, which is myeloma that has spread outside of the bone marrow to other soft tissues and organs. Another difficult-to-treat adjunct of myeloma is plasma cell leukemia (PCL). This is a rare, yet aggressive variant of myeloma, characterized by high levels of plasma cells circulating in the peripheral blood. PCL can be an original diagnosis (primary PCL), or originate as a secondary leukemic transformation of myeloma (secondary PCL). Finally, AL-Amyloidosis is a plasma cell disorder in which the light chain component of antibody proteins become misfolded. These misfolded light chains become deposited in tissues including heart, kidney, skin and liver as the substance amyloid and interfere with normal tissue function. Studies in AL-Amyloidosis are being actively discussed.

The MMRC is also exploring novel agent combinations such as the previously reported company-sponsored trial, opened shortly. In this study, the novel agent selinexor is being tested in combination with companies to identify novel combinations of immune approaches including other types of antibodies, engineered T-cells and vaccines to advance into clinical trials.

The MMRC is also exploring novel agent combinations such as the previously reported company-sponsored trial, which opened this past spring with the company Karyopharm Therapeutics. In this study, the novel agent selinexor is being tested in combination with lenalidomide and dexamethasone. The Phase I study of MPDL3280A from Genentech, which is an anti-PDL1 immune checkpoint antibody, will be given in combination with Revlimid to early relapsed patients and as a single agent to patients who have residual disease after autologous stem cell transplant. MMRC investigators and the research team at the MMRC are working closely with companies to identify novel combinations of immune approaches including other types of antibodies, engineered T-cells and vaccines to advance into clinical trials.

Finally, trials focused on testing drugs that are directed against specific genomic alterations present in myeloma tumor cells in subpopulations of patients are rapidly advancing to the clinic and will be opened in the MMRC.

If you have any questions about the clinical trials that have been initiated over the last 18 months, or believe you may be eligible, please call our nurse hotline at 1-866-603-6628.
In September, the MMRF announced that the landmark MMRF CoMMpass Study, the largest long-term genomic study ever conducted in myeloma, reached a major milestone with full enrollment—an unprecedented 1,000 patients participating. To put this in perspective, in relative terms, 1,000 patients with multiple myeloma is the equivalent of more than 1.2 million patients with type 2 diabetes.

The global study is mapping the genomic profile of each enrolled patient in order to advance our understanding of disease progression, including patient response to therapies. Tissue samples will be genetically analyzed when the patient is first diagnosed, and then each time there is a change in treatment, over the course of eight years.

Data from the study will improve our understanding of the disease biology at diagnosis, and how it changes in response to various treatment interventions—helping us to better anticipate optimal treatment strategies. It will also be possible to use future MMRF CoMMpass Study data to identify and validate the unique disease drivers of myeloma, and improve our ability to predict these drivers for individual patients. This understanding will help improve treatment interventions and clinical outcomes. Additionally, these data may help us to further understand the incidence and outcomes among patients from unique populations, such as African Americans.

The Multiple Myeloma Research Foundation CoMMpass Study is the most comprehensive long-term genomic study ever conducted in myeloma. Ultimately, it will help accelerate the development of novel, personalized treatments for patients, and advance our mission of reliably curing multiple myeloma.

“Beyond identifying novel biomarkers and therapeutic targets, the results will help physicians make more informed and customized treatment decisions for their patients through data that show which individual and combined therapies work based on a specific profile, and will also help us identify mutations,” said Principal Investigator Sagar Lonial, M.D., FACP, Professor and Executive Vice Chair in the Department of Hematology and Medical Oncology, and Chief Medical Officer, Winship Cancer Institute, Emory University. “This deep understanding ultimately leads to better, more precise care, as well as the promise of a cure.”
The MMRF Precision Medicine Model is changing everything.
Its incredible results depend on people like you.

Dr. Nizar Bahlis, University of Calgary, Calgary, Alberta, Canada
Dr. Bahlis’s work will investigate how myeloma cells become resistant to the IMiDs class of drugs (Thalidomide, Revlimid, Pomalyst). He has analyzed the genome of myeloma cells resistant to IMiDs and identified several potential mechanisms to explain this resistance. In this proposal he intends to study these mechanisms with the aim to develop novel therapeutics to overcome them.

Dr. Esteban Ballestar, Bellvitge Biomedical Research Institute, Barcelona, Spain
Dr. Ballestar is interested in understanding the epigenetic mechanism of DNA methylation as it relates to myeloma cells and the cells of bone formation (osteoblasts) and bone resorption (osteoclasts) during the process of bone destruction that often accompanies myeloma. He will investigate the possibility of using methylation as a marker for myeloma bone disease status and response to drugs.

Dr. Alan Lichtenstein, Brentwood Biomedical Research Institute, Los Angeles, CA
Dr. Lichtenstein will examine the sensitivity of cells to inhibitors which target the RNA of the c-myc gene, called IRES, which is induced in myeloma cells as a survival mechanism when treated with Velcade (bortezomib). Inhibition of this IRES RNA may offer new treatment strategies for patients who develop Velcade (bortezomib) resistance.

Dr. Robert Orlowski, University of Texas, MD Anderson Cancer Center, Houston, TX
Dr. Orlowski’s work will focus on high-risk patients whose myeloma cells harbor the 17p deletion and p53 loss. Using shRNA technology, he will identify genes necessary for the survival of these myeloma cells and develop new treatment strategies based on inhibition of the function of these novel targets.

Dr. Fenghuang Zhan, University of Iowa, Iowa City, IA
Dr. Zhan has already identified gene NEK2 as upregulated in myeloma cells of patients achieving Complete Remission (CR) and early relapse of multiple myeloma, and found it plays a role in increasing the genomic instability of myeloma cells, which is a hallmark of increased tumor cell survival, drug resistance, and poor prognosis. This grant will enable a continuation of that work, wherein he will examine the exact role of NEK2 in promoting tumor cell survival and also the impact of NEK2 inhibitors in preventing relapse.

In 2015, the MMRF funded $1,375,000 in Senior Research and Research Fellow Awards. The MMRF acknowledges generous contributions from Amgen, Bristol-Myers Squibb, Genentech, Millennium, Onyx, Celgene, and Novartis in support of the awards.

This year has been remarkable.
The end-to-end model we built is working — and the results are in the pipeline. We are currently conducting 18 clinical trials within each of the most promising drug categories. Three drugs are currently being evaluated for FDA approval. And we have reached the important milestone of enrolling 1,000 patients in the landmark MMRF CoMMpass Study, the cornerstone of the MMRF Precision Medicine Model.

We need funding now for all three components of the model.

■ Databank: Building a critical mass of data to deepen our understanding of the disease requires an uninterrupted flow of vital research.

■ Learning Network: Extensive support is required to enable our teams of researchers and clinicians to pool their knowledge and share discoveries.

■ The Clinic: Clinical trials of treatments with the greatest potential for all myeloma patients will stall without funding; your support helps accelerate their progress.

Our model works when the people behind it are enabled to do their parts — patients, doctors, academic researchers, and industry partners. It all requires funding. It is the element that makes the work possible.

Without your generosity, the entire process slows. New drugs could be delayed instead of fast-tracked. Please take a moment and fill our end-of-year fundraising envelope as generously as you can.

Donate now and the Elseys will double it.
When Kathy Elsey was diagnosed with multiple myeloma, she and her husband Dr. Bruce Elsey, co-founders of Dr. Elsey’s Precious Cat Litter products, established Dr. Elsey’s Fund to Cure Cancer. Their generous contributions of nearly $8 million since 2009 have rapidly accelerated the development of new treatments and driven the MMRF closer than ever toward finding a cure. Now they will match your contribution, dollar for dollar, until December 31, 2015.

Please join them. Give today at themmrf.org/donate
Meet four MMRF cancer fighters
Our team members bring different strengths, and are united by their passion, determination, and commitment to cure cancer now.

**Thomas Conheeney**, **MMRF Board Member**

The MMRF is pleased to announce that Thomas Conheeney, retired president of SAC Capital, has joined our Board of Directors. “Tom’s commitment to our work and his deep experience in the areas of capital markets and finance will be invaluable to the Foundation and our Board,” said Walter M. Capone, Chief Executive Officer and President of the MMRF.

Tom was appointed President of SAC Capital in July 2008. He joined SAC in October 1999 as Chief Operating Officer. Prior to joining SAC, Tom was President of Investment Management Services, Inc. (“IMS”) from 1996 to 1999. He joined Moore Capital/IMS in 1993 and served as its Director of Trading Operations and then Vice President until IMS split off from Moore in 1995. Prior to joining Moore Capital/IMS, from 1986 to 1993, Tom held various positions in the equity division at Goldman, Sachs & Co., becoming Vice President in 1990. He retired from SAC December 2014, and now serves as a Board Member for a number of organizations, including the King School in Stamford, CT where he is President of the Board.

**Steven Shak, M.D., MMRF Board Member**

The MMRF eagerly welcomes Steven Shak, M.D., to our Board of Directors. Steve is a co-founder of Genomic Health, Inc., serving as Chief Scientific Officer since 2002 and Chief Medical Officer from 2000-2013. Under his leadership, Genomic Health created innovative molecular diagnostic methods and has maintained an 80% product development success rate.

Steve served for 14 years in various roles in Discovery Research and Medical Affairs at Genentech, Inc., a biotechnology company dedicated to using human genetic information to treat serious medical conditions. “Steve has been on the leading edge of diagnostic and therapeutic advances in oncology for over two decades, augmenting the areas of greatest promise as we pursue our mission for cures,” said Walter M. Capone, Chief Executive Officer and President of the MMRF.

Before joining Genentech, Steve was an Assistant Professor of Medicine and Pharmacology at New York University School of Medicine. He holds a B.A. in chemistry from Amherst College and an M.D. from New York University School of Medicine, and did his post-doctoral work at University of California, San Francisco.

**Mary DeRome, Translational Research Manager**

As Translational Research Manager for the MMRF, Mary DeRome helps scientists conduct preclinical research. This research helps transfer knowledge about multiple myeloma from the laboratory to the clinic.

Mary is well suited to “enabling scientists to do their work,” as she puts it. She comes to the MMRF with a B.S. in Chemistry, an M.S. in Molecular/Cell Biology, and an extensive scientific and investigative background. She spent 12 years as a senior investigator in oncology drug discovery at Bayer HealthCare, then seven years in nano-technology vaccine development at Artificial Cell Technologies. “I worked in pharma for 12 years, but that is not like this.”

**Michael Hund, Director of Development**

Michael Hund, Director of Development for the MMRF, was raised on a cattle ranch in a small, rural farming community where everybody depended on each other. “Growing up in a place where community was so important,” he says, “I realized that accomplishing great things is not impossible if you have the right people to do it.”

Michael, who worked on behalf of children with terminal cancer during his 10 years at Paul Newman’s Hole in the Wall Gang Camp, says the MMRF “has the right people in place to accomplish a very lofty goal. Every day I’m motivated by the fact that we are within grasp of finding a cure for this illness and I believe it with every ounce of my body.”

“We have seen it to be true,” he explains. “Just over a decade ago, there were no treatments, no opportunities for patients. Now we have seven, and more on the way. We have tripled life expectancy. We’ve had a track record of results and have built the model that’s enabled us to do this — this incredible, powerful engine that is racing toward the finish line of a cure. It needs fuel. It needs funding. There’s no greater motivator than knowing that if I can put some fuel in that engine, it can go even faster and move even quicker.”

Mary, Michael, and the entire MMRF dedicated team are working hard to find a cure for multiple myeloma. “We’re giving people the opportunity to change the entire landscape of how cancer research is done, to be part of something bigger than themselves, a community that can accomplish these phenomenal results. Our focus is to find a cure. That is our end result, our vision, our goal. When you hear about the tenacity and accelerated pace, you want to be part of that momentum.”

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Mary DeRome, Translational Research Manager

As Translational Research Manager for the MMRF, Mary DeRome helps scientists conduct preclinical research. This research helps transfer knowledge about multiple myeloma from the laboratory to the clinic.

Mary is well suited to “enabling scientists to do their work,” as she puts it. She comes to the MMRF with a B.S. in Chemistry, an M.S. in Molecular/Cell Biology, and an extensive scientific and investigative background. She spent 12 years as a senior investigator in oncology drug discovery at Bayer HealthCare, then seven years in nano-technology vaccine development at Artificial Cell Technologies. “I worked in pharma for 12 years, but that is not like this.”

“We are constantly speaking with our academic and industry partners about new avenues of research. For example, if they have ideas for therapy in a different type of cancer that we think might be good for our patients, we will work with them to develop the idea and help provide resources to investigate its use in our patient population. It’s an excellent model — we’re a small, lean organization. We’re very close to the patients. What we do impacts them directly, and the answers we get from using their samples helps all multiple myeloma patients.”

In addition to providing tissue, analysis, and other tools for facilitating research, Mary directs the MMRF’s competitive peer-reviewed grant programs. But unlike at other foundations, “here, grant-making is only a part of what we do. Other foundations are not involved in data generation, clinical trial start-up and patient enrollment, which help speed the discovery of a cure for multiple myeloma. We are doing work that has not been done.”

From Michael’s perspective, “We’re giving people the opportunity to change the entire landscape of how cancer research is done, to be part of something bigger than themselves, a community that can accomplish these phenomenal results. Our focus is to find a cure. That is our end result, our vision, our goal. When you hear about the tenacity and accelerated pace, you want to be part of that momentum.”

Next on Michael’s agenda? His goal is to work himself out of a job. “My job is to raise funding for this, to get support, to build a community so that eventually I’m unemployed. That would be the greatest thing. It would mean we found a cure and could move on to the next cancer.”
MyMMRF News

Connecting patients and caregivers to knowledge and treatments

Knowledgeable patients are empowered patients. MyMMRF provides you with the latest information in myeloma and connects you to leading doctors and researchers. It also connects you to promising, potential new treatments that are available only through clinical trials.

MMRF Patient Summits empower patients and caregivers through education

Being well-informed is so important. There is no better place to learn about multiple myeloma, current treatment options, clinical trials, and optimal disease management recommendations than at a live Patient Summit.

The MMRF conducts these educational programs in collaboration with leading myeloma cancer centers across the country. Speakers include renowned clinicians and researchers, and patients who share their experiences in navigating the disease. The full-day program provides an opportunity to connect with the myeloma community, ask questions, and learn about the latest advancements toward effective treatments and cures.

The sessions are uplifting, empowering, and informative. This year, over 1,500 patients and their families attended MMRF Patient Summits held in New York, Atlanta, Boston, Chicago, and Seattle.

The agenda for the all-day seminars and workshops are offered free of charge, and feature comprehensive sessions on a variety of topics:

- Myeloma 101: Prognosis and Risk
- Treatment Options for Newly Diagnosed Patients
- Stem Cell Transplantation
- Treating Relapsed/Refractory Disease
- Supportive Therapies: Managing Side Effects of Myeloma
- Promising Clinical Trials
- Ask the Experts: Question & Answer

You can view video recordings of the programs on our website. Watch them at themmr.org/patient.

New clinical trial finder works with patients’ profiles

Our new clinical trial tool is easy to use and delivers results specific to your individual criteria. It is available through the MMRF CoMMunity Gateway, an online community of MyMMRF that also offers discussion forums, treatment information, and more.

This new search tool is user-friendly, convenient, and “smart” — it uses each MMRF CoMMunity Gateway member’s profile to match patients to appropriate trials. It uses criteria that you provide such as myeloma status, location, prior treatment history, and more. It also allows you to save your search criteria and your searches, and compare them as well.

By providing patients with customized trial results, we will be able to match patients to potential life-extending tools and therapies that are not yet available to everyone. The MMRF empowers you to take control of your myeloma by utilizing this tool.

Call a nurse

We are able to provide educational and other services to patients and caregivers thanks to generous support from our partners in the pharmaceutical industry.

Bristol-Myers Squibb • Celgene • Genentech • Janssen • Novartis • Onyx Pharmaceuticals an Amgen Subsidiary • Takeda

Join the MMRF CoMMunity Gateway at www.MMRFCoMMunityGateway.org
Meet the MMRF Patient Support Nurses

Linda Northcutt, Team Manager, RN, BSN, MBA, PHN, CCM, has 39 years of experience as a registered nurse, as well as research experience. Linda received the Navy Achievement Medal for providing training to Corpsman and Guamanians to help increase the number of licensed nurses on the island of Guam. She attended Mercy School of Nursing, Texas Tech University, East Texas University, University of San Diego and University of Phoenix.

Millicent Douglas, RN, BSN, OCN, has been a registered nurse for 34 years, specializing in oncology and psychiatry. Millicent spent the majority of her career educating others. She taught nursing at the university level, but her passion for learning and teaching surpasses the walls of a classroom. Millicent is fiercely committed to educating her patients as well. She received her BA and BSN from Northeast Louisiana University.

Norma “Katy” Welch, RN, OCN, has been a registered nurse for 28 years. Katy specializes in working with multiple myeloma patients. She worked with the Multiple Myeloma Institute in the transplant and myeloma program and acted as a traveling nurse for the Myeloma Research and Transplant Institute. Katy completed her undergraduate studies at the University of Texas at Texarkana and attended William Buchanan School of Nursing at Texarkana College.

To speak with an MMRF nurse specialist, call 866-603-6628.

IRONMAN® Lake Placid

On July 26, 110 MMRF Team for Cures athletes took on IRONMAN® Lake Placid, a grueling 140.6-mile race that includes a 2.4-mile swim in Mirror Lake, a 112-mile bike ride through the mountains of the Adirondacks, and a 26.2-mile run. The athletes, 60 percent of whom had never heard of the MMRF when they joined the team, raised over $900,000.

Athletes and families made a huge impression along the route, and the MMRF Team for Cures jerseys raised awareness and visibility for the MMRF. Kelley Ward, MMRF Endurance Events Manager, said, “We love that this race provides a way for athletes who don’t necessarily know about the MMRF to become our champions. By race day, they are all here because they want to help cure cancer NOW.”

The top fundraisers for the MMRF Team earned the “bucket list dream” of triathletes, a spot in the IRONMAN World Championships in Kona, Hawaii, on October 10. The top four were:

- Chuck Ellison, an MGUS patient
- Jeannie Moody, a multiple myeloma hematology nurse at Memorial Sloan Kettering Hospital
- Keli Engleson, a niece of a patient
- Dave McQuillan, a friend of a patient

Of note, two of the athletes on the team are living with multiple myeloma or MGUS. Chuck Ellison, of Fairhope, AL, was diagnosed with Monoclonal Gammopathy of Undetermined Significance or MGUS in 2013. Craig Finkbeiner, of Midland, MI, has endured over 75 rounds of chemo and three stem cell transplants. He took on the race while fighting the effects of his treatments.

The MMRF is the exclusive and Official Charity Partner of IRONMAN Lake Placid, the oldest and most prestigious IRONMAN race in the continental U.S. We are filling spots now for the 2016 IRONMAN Lake Placid team. Our VIP perks and amenities make training more meaningful and race day (Sunday, July 24, 2016) more powerful.

The MMRF is also a charity partner of two IRONMAN 70.3 races in 2016 – Arizona on October 16th, and the newly announced, Atlantic City on September 18th.

Visit themmrf.org/EnduranceEvents

At the MMRF we have seen evidence that the more knowledgeable you become, the more empowered you are to make the decisions and choices that lead to improved care. The MMRF nurse specialists are an invaluable source of information and support that you can access at 866-603-6628 or through discussion groups within the MMRF CoMMunity Gateway — part of the MyMMRF online resource center for patients and caregivers. They receive over 7,500 calls a year from patients and caregivers. Here are the faces behind the phone calls.

Linda Northcutt, Team Manager, RN, BSN, MBA, PHN, CCM, has 39 years of experience as a registered nurse, as well as research experience. Linda received the Navy Achievement Medal for providing training to Corpsman and Guamanians to help increase the number of licensed nurses on the island of Guam. She attended Mercy School of Nursing, Texas Tech University, East Texas University, University of San Diego and University of Phoenix.

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Karen E. Andrews, MMRF Co-Founder and member of the MMRF Board of Directors, was also honored with the MMRF Spirit of Hope Award. Ms. Andrews co-founded the MMRF in 1998 with Kathy Giusti, her twin sister. Ms. Andrews also serves as the Senior Vice President and General Counsel for the March of Dimes.

Presenting sponsors included: Takeda Oncology and Janssen Oncology. “We are extremely grateful for the support and partnership of so many courageous patients, their families and industry leaders. Their support and continuous collaboration will enable us to continue to build game-changing models in tissue banking, genomics, clinical trials and open access data sharing, driving leading-edge research and ground-breaking new treatments until we overcome this disease,” said Walter Capone, President and Chief Executive Officer of the MMRF.

The over $2,000,000 raised comes at a transformational time in the history of multiple myeloma research.
Bob has fielded teams in both Chicago and the Twin Cities races every year since his diagnosis and has personally been a part of each walk/run in some way. It is his hope that a cure will be found soon so that multiple myeloma, if not eradicated in his lifetime, becomes a chronic, manageable disease for all who are affected.

Harold attributes his success at raising over $130,000 for the MMRF over the past 15 years to support from his Naval Academy classmates and his submarine shipmates. In 2008, Harold celebrated 10 years as a myeloma survivor, so he set his goal at $10,000. Until that year, Harold had always had a goal of $6,400 in recognition of the fact that most of his contributions were from his Naval Academy Classmates of the Class of ’64.

Harold was diagnosed with multiple myeloma in 2009. Today, he is in remission. “Twenty years ago, before the Multiple Myeloma Research Foundation existed, people who got the disease were only expected to live a couple of years. That has all changed,” he explains. “Drugs on the market that came from MMRF research have helped me and many others.” Grateful for the aggressive efforts by the MMRF, Moss felt he had to do something. “I wanted to help raise money, so I looked at what I like — good music, wine and great food. From that, I started Wine & Dine in the D.”

Wine & Dine in the D is a strolling dining experience featuring cuisine from 20 of Metro Detroit’s finest restaurants, wines, craft beer and spirits from Michigan and around the world, and live jazz entertainment. This year’s event on October 22 began with a multiple myeloma roundtable by prominent doctors in the field. Since its inception in 2005, Wine & Dine in the D has raised over $500,000 for the MMRF. Visit wineanddineinthed.org to learn more.

Eastern Iowa Miles for Myeloma Run/Walk

Dan Cummins and his wife Laurie started an event in their hometown in honor of Dan’s brother Doug and his friend Dan Dwyer, who also suffered from multiple myeloma. Their first Eastern Iowa City Miles for Multiple Myeloma Run/Walk was focused on bringing together people who have been touched by multiple myeloma in a supportive and caring environment. Fifteen charter walkers raised $4,000. By last year, over 600 people were walking, raising nearly $35,000. This year’s event was held on September 27 and raised another $25,000. As Dan’s father, Phil Cummins, says, “Cancer of any sort is dreadful, and there’s not much you can do when you’re not a doctor, but you can raise money.” Visit milesformm.com

Anyone with a passion to cure multiple myeloma and an idea for an event can raise money to accelerate the research. Every dollar counts. In 2015, Independent Events will raise over $1,000,000 for the MMRF.
The MMRF has a compelling story to tell and the world wants to hear it.

Kathy Giusti testifies at U.S. Senate committee
On September 16, Kathy Giusti spoke before the Senate committee on Health, Education, Labor and Pensions (HELP) on the value of electronic health records.

We take Google searches and cloud storage for granted, but scientists and medical professionals do not have these luxuries when they are trying to access patient data to search for treatments and cures.

Kathy Giusti describes how the MMRF is sharing data through a global learning accelerator.

The MMRF Online: themmrf.org/stories
Help us break through faster

Fund the MMRF Precision Medicine Model

The MMRF has built a three-pillar, end-to-end model in precision medicine that collects a wide range of patient data, encourages the open sharing of data worldwide among researchers, and accelerates clinical trials to make treatments available faster. It is revolutionizing and accelerating the way cancer research is conducted. Each and every component requires funding.

Please support the MMRF campaign.

WE ARE CURING CANCER NOW

PLEASE SUPPORT THE MMRF CAMPAIGN.
DONATE AT THEMMRF.ORG/DONATE