ABOUT THE MULTIPLE MYELOMA RESEARCH FOUNDATION

The Multiple Myeloma Research Foundation (MMRF) was established in 1998 by identical twin sisters Kathy Giusti and Karen Andrews shortly after Kathy’s diagnosis with multiple myeloma. Kathy and Karen soon learned that little progress against this disease had been made in decades, and that myeloma patients had few treatment options. They decided that it was time to accelerate change.

Working with its partners in industry, research, government agencies, and academia, the MMRF has helped launch ten new treatments in the past decade, an achievement that has almost tripled the life expectancy for myeloma patients. As a patient-founded organization, the MMRF stands with those who are battling multiple myeloma—patients, families, caregivers, doctors, and researchers—and is focused squarely on speeding the discovery of a cure. We see a world where every person has precisely what he or she needs to prevent or defeat multiple myeloma.

As the multiple myeloma community’s most trusted source of information, the MMRF supports patients from the time of diagnosis throughout the course of the disease. All information on the MMRF website (www.themmrf.org) is organized by disease stage, so patients can get the information they need, when they need it.

To learn more about the MMRF, visit www.themmrf.org or call (203) 229-0464.

To speak to a Nurse Patient Navigator at the Patient Support Center, call 1-866-603-MMCT (6628) or email patientnavigator@themmrf.org.

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INTRODUCTION

Caregivers (partners, family members, and close friends) play a vital role in helping multiple myeloma patients manage their disease and navigate treatment options. The surge in the number of new drugs that have become available (10 new myeloma drugs approved in the last 12 years!) has made multiple myeloma management an exciting but confusing arena. As a result, caregivers may not be confident in their knowledge of current standards of care, how drugs are used, what to expect while patients receive therapy, and—perhaps most importantly—how they can best help the myeloma patients in their daily living. Additionally, as optimal multiple myeloma management may involve participation in a clinical trial, it is beneficial for caregivers to be aware of myeloma clinical trials in their area.

Providing care to a patient with multiple myeloma encompasses supporting dietary needs, daily activities and exercise, managing symptoms, providing emotional support, and coordinating health care. For caregivers, this may require a considerable personal sacrifice, potentially involving a commitment of many years, and it may exact an emotional, physical, psychosocial, and financial toll. A recent study revealed that caregivers have more stress and anxiety than patients, which may be due to their fears regarding declines in patients' health, the risk of disease recurrence, and feelings about death and dying.

At the MMRF, we recognize that the need to support caregivers is paramount. We know that myeloma patients and their caregivers are interested in learning about therapies, benefits and risks of treatment, and disease prognosis. Greater knowledge in these areas will help to alleviate fears, anxiety, and uncertainty and empower caregivers to advocate for the treatment options that are most likely to yield the best outcome for their loved ones.

For more information about multiple myeloma and its treatment, please refer to the companion brochures Multiple Myeloma Disease Overview and Multiple Myeloma Treatment Overview and the MMRF website—www.themmrf.org.
ABOUT MULTIPLE MYELOMA

DIAGNOSIS

Multiple myeloma is a blood cancer that develops in the bone marrow. In myeloma, plasma cells, which are normal antibody-producing cells, transform into cancerous myeloma cells. Myeloma cells produce large amounts of abnormal antibodies called monoclonal (M) proteins. Myeloma cells also crowd out and block the production of normal blood cells in the bone marrow. Multiple myeloma affects the bone, the blood, and the kidneys.

Blood and urine tests, as well as bone marrow biopsy, are performed to confirm a diagnosis of myeloma, to assess the extent of the disease, and to monitor progress once treatment is started. Genomic sequencing is conducted by analyzing the DNA from the myeloma cells taken from a small amount of bone marrow. Tests are conducted as part of the initial diagnosis and may be repeated periodically. Additionally imaging tests that could include x-rays, MRIs, CT scans, and PET scans may be ordered. It is important for patients to have all the appropriate tests done, as the results will help the doctor better determine treatment options and prognosis.

Lab tests.
TREATMENT TEAM

During treatment, several members of the health care team will be involved in the patient’s care. As a myeloma specialist, the doctor is considered the quarterback of the health care team. However, treatment decisions are ultimately based not only on this doctor’s recommendations but on the patient’s treatment goals and preferences.

A nurse practitioner and/or a physician assistant may serve as an extension of the myeloma specialist; one or more of these individuals may meet with the patient during office visits, and any of them can answer patient and caregiver questions.

The clinical research nurse or an infusion nurse usually administers the prescribed treatment, and the nurse coordinator relays patient or caregiver concerns to the team and can also treat some disease symptoms or treatment side effects.

The social worker is an excellent resource and can help connect the patient and caregiver with extra social support. For example, a social worker can provide information about caring for young children at home, dealing with aging parents, housing and transportation needs during treatment, or accessing financial support to cover the costs of treatment.

The myeloma treatment team.
**TREATMENT PLAN**

The treatment options for patients with multiple myeloma—at all stages and in all forms of the disease—are more plentiful and varied than ever before.

The goal of therapy is to induce a remission (a reduction in plasma cells/M protein to a very low level) and to achieve that response as quickly as possible to minimize the risk of organ damage, improve quality of life (reduce pain, lessen fatigue), and minimize the occurrence and/or severity of side effects.

**Goals of myeloma therapy.**

- Induce remission (a reduction in plasma cells/M protein to a very low level)
- High response rate; rapid response
- Improve performance status
- Minimal side effects
- Prolong overall survival and preserve function and quality of life

The choice of a patient’s initial treatment depends on many factors, including the features of the myeloma, the risk of potential side effects, and the patient’s treatment goals. Treatment options are similar regardless of whether patients undergo stem cell transplantation. A stem cell transplant is a procedure in which blood-forming cells are collected from the patient or a donor, stored while the patient receives high-dose chemotherapy to eliminate the myeloma cells in his or her blood and bone marrow, then re-administered to the patient. Because high-dose chemotherapy can also reduce the normal cells in the bone marrow, a stem cell transplant can help to replenish the bone marrow.
Patients who are candidates for transplant may choose to receive high-dose chemotherapy followed by a stem cell transplant after three or four rounds (cycles) of initial therapy (that is, the first treatment a patient receives after the myeloma diagnosis is confirmed; it's also known as induction therapy). Or they may decide to continue their initial therapy and consider transplant later. Maintenance therapy (treatment given when a patient is in remission to help prevent a relapse) may be considered following transplantation.

**Myeloma treatment plan.**

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**Is the patient a candidate for an autologous stem cell transplant?**

- **Yes**
  - 3–4 cycles of therapy (induction)
  - • 3-drug regimens (generally preferred): RVD, VCD, IRD, KRD
  - • Clinical trial
  - Stem cell collection and storage
  - High-dose chemotherapy and autologous transplant
  - Consolidation and/or maintenance
  - Supportive care
  - Any of the regimens listed for transplant candidates
  - • 2-drug regimen, particularly for patients with health/side effect concerns
  - • Clinical trial

**GETTING THROUGH THERAPY**

Caregivers, as part of the health care team, play a crucial role in the treatment process. They ensure that the patient attends appointments, serve as another set of ears for information relayed to the patient, and note symptoms and side effects and are able to report them to the health care team. Additionally, caregivers can ensure that the patient takes any prescribed medications in the correct dosages and at the appropriate time. Above all, the caregiver helps the patient optimize nutrition, self-care, sleep, and exercise—all while providing love and support!
Key questions to ask the health care team.

- What are the treatment choices?
- What are the risks and benefits of each?
- What can I do to prepare for treatment?
- How will treatment affect my normal routine?
- What are the side effects and how can I minimize the risk of side effects?
- What resources are available for me and my family?
- What is the best way to get in touch with you for questions or emergencies?

SEEKING AND RECEIVING SUPPORT

As a caregiver, it is possible that you may ignore your well-being while focusing on the needs of the patient in your care. However, caring for yourself is important: it recharges you and enables you to provide steady, strong support to the patient you care for. Below are some strategies to cope with physical and emotional stresses you may experience.

Coping and support for myeloma caregivers.

1. Learn enough about multiple myeloma to help your loved one make decisions about his/her care.
2. Ask questions about treatment options and side effects.
3. Look into support groups where you can meet and speak with others who are caregiving or where your loved one can talk to others facing multiple myeloma.
4. Establish and maintain a strong support system for yourself.
5. Encourage your loved one to establish and maintain support as well.
6. Friends and family are vital. Enlist help so you can share the responsibilities. Be specific about the help you need.
7. Educate yourself and your loved ones about multiple myeloma so that you and those around you know what to expect.
8. Provide care for yourself: nutrition, exercise, sleep, spirituality...see your own health care provider, too.
9. Maintain some normalcy (work, relationship, travel, social activities both with and without loved one).
Concerns of the caregiver and coping mechanisms.

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RESOURCES
At the MMRF, we are dedicated to supporting the myeloma community by providing a broad range of resources for those living with myeloma, as well as their caregivers. We are here to help guide you through your multiple myeloma journey every step of the way.

MMRF Resources

• Speak to a MMRF Nurse Patient Navigator from the Patient Support Center for answers to your questions about disease management, treatments, clinical trials, and assistance with finding financial and other available resources.
  − Telephone: 1.866.603.6628,
  − Monday—Friday, 9:00 a.m. to 7:00 p.m. ET
  − Email: patientnavigator@themmrf.org

• The MMRF monthly newsletter delivers the latest myeloma MM information (themmrf.org/mmreg).

• Get the latest myeloma updates on the MMRF website (themmrf.org/education) and follow the MMRF on Facebook and Twitter.

• The MMRF Multiple Myeloma Disease Overview and Multiple Myeloma Treatment Overview brochures provide information about the basics of myeloma and treatment options. You can download it by following this link themmrf.org/resources.

• Myeloma Patient Summits are held in multiple cities across the US each year themmrf.org/patient).

• Find an MMRF Support Group at themmrf.org/supportgroups.

• Search for a clinical trial in your area or let MMRF Nurse Patient Navigators help guide you through the process (themmrf.org/trialfinder).

Technology Tools

• For websites and mobile applications, please go to themmrf.org/caregiverscorner.

Financial Support

For information on reimbursement assistance programs for myeloma drugs, please go to themmrf.org/financialsupport.
Attend a Multiple Myeloma Patient Summit
Learn about standard and emerging therapies including stem cell transplants, promising clinical trials, and more for optimal disease management. Attend a complimentary symposium for all the information you need to make well-informed decisions about your treatment and care.

To register, view past summits and the complete calendar, visit: themmrf.org/patient

View Past Programs on Demand
Access our archive of recorded Patient Summit symposia and webcasts. Hear expert perspectives on key clinical research and the rapidly evolving myeloma treatment landscape.

All available online, and free, at: themmrf.org/education

Find a Clinical Trial Near You
Clinical trials are critically important in order to develop new myeloma treatments and better understand the biology of the disease. The more people who enroll, the faster we can find answers. Patients who enroll in clinical trials have the opportunity to be among the first to receive the newest drugs or drug combinations in development and receive close monitoring.

To find a clinical trial near you, visit: themmrf.org/trialfinder
Contact one of our Patient Nurse Navigators at the Patient Support Center

866-603-MMCT (6628)

Hours: Mon-Fri, 9am-7pm ET
Email: patientnavigator@themmrf.org