[ACT]IVATED MYELOMA | VETERANS AND FIRST RESPONDERS

RESOURCE GUIDE | FEATURING DR. KRINA PATEL

Patient Empowerment Network

EXPERT [ACT] IVATION TIPS

[ACT]IVATION TIP: "If you notice that anything is off, you're not feeling well, something is wrong with your labs, make sure to mention that to your physicians, so they can diagnose you correctly. If you have a diagnosis of cancer, talk to your teams; they can point you to resources out there to help, including financial and emotional resources." - Dr. Krina Patel

[ACT]IVATION TIP: "The mental aspect of cancer treatment is really important. Use your myeloma diagnosis to help others. Find patient groups so that you get access to their resources. In a patient group, you have the ability to talk to someone about what happened and be able to go through that process of talking to someone as well." - Dr. Krina Patel

[ACT]IVATION TIP: "All of us have different susceptibility to cancer based on how our immune system repairs itself, but it's also our exposures. We know for veterans exposed to Agent Orange and 9/11 first responders that whatever they were exposed to during that process led to their plasma cells becoming myeloma at a much younger age, and a lot have a more aggressive disease than the indolent slow-growing myeloma." - Dr. Krina Patel

[ACT]IVATION TIP: "A big question I get is, How can we say something caused my myeloma? It comes back to how many people were exposed and how many people actually got that disease. If you were exposed to something like Agent Orange or major petrochemical spill, that is worth noting at least, even though I most likely won't be able to tell you it definitely caused the myeloma." - Dr. Krina Patel

RISK FACTORS AND CONSIDERATIONS

Risk Factors

An [ACT]IVATED patient is informed, empowered, and engaged in their care.

- Veterans from the Vietnam War and other people exposed to the herbicide Agent Orange have an increased risk of developing monoclonal gammopathy of undetermined significance (MGUS), which is a precursor to multiple myeloma.
 - If diagnosed with MGUS or myeloma that was caused by exposure to Agent Orange, you may be eligible for Veterans Affairs (VA) disability compensation. Learn more from the VA here.
- Firefighters and 9/11 first responders have about twice the average risk of developing MGUS, which can progress to myeloma.
 - o These firefighters also exhibit a younger age of onset and more aggressive disease than usual.

Support for Veterans With Myeloma Through the PACT Act

- The PACT Act expands VA healthcare and benefits for veterans exposed to open burn pits, fine particulate matter (PM2.5) from airborne hazards, and more.
- Additionally, the VA is conducting a scientific review to determine the relationship of multiple myeloma outside of the head and
 neck and toxic exposures for service members who were deployed to Iraq, Afghanistan, Somalia, Djibouti, Egypt, Jordan, Lebanon,
 Syria, Yemen, Uzbekistan, and Southwest Asia.

MYELOMA RESOURCES

- Patient Empowerment Network
- American Cancer Society
- Cancer Support Community
- HealthTree Foundation
- International Myeloma Foundation
- The Leukemia & Lymphoma Society (LLS)
- Multiple Myeloma Resource Foundation
- National Comprehensive Cancer Network
- National Cancer Institute
- Veterans Against Myeloma

VA RESOURCES

- Familiarize yourself with VA disability compensation.
- Read this <u>booklet</u> explaining federal benefits for veterans, dependents, and survivors.
- Find a <u>VA location near you</u>.
- HealthEVet: You can refill prescriptions, keep track of medications and upcoming VA appointments, talk to your healthcare team, and view/enter your health information.
- If you were exposed to Agent Orange, find specific resources and studies here.
- You can get a free Agent Orange Registry health exam. Learn more here.

CARE CHECKLIST

- 2 1. **Schedule a meeting with your doctor.** Discuss diagnosis and treatment options with your oncologist or myeloma specialist. Make sure you share any relevant exposures.
- 2. **Get diagnostic tests and staging.** Undergo necessary tests, including blood work, bone marrow biopsy, and imaging. Determine the stage of your myeloma to guide treatment decisions.
- 3. **Determine treatment plan.** Explore treatment options, which can include chemotherapy, immunomodulatory drugs, targeted therapies, and stem cell transplantation. Discuss potential side effects, benefits, and risks with your healthcare team.
- 4. Access VA benefits. Apply for benefits if you haven't already. Consult with a Veterans Service Officer (VSO) to navigate the claims process and to ensure you receive appropriate care and compensation.
- 5. **Seek emotional support.** Talk openly with loved ones, consider talk therapy, and connect with relevant support groups for veterans or first responders with multiple myeloma.
- 6. Maintain a healthy lifestyle. Discuss a plan with your care team that includes nutrition, exercise, and stress/pain management.
- 7. **Stay engaged.** Communicate regularly with your healthcare team, ask questions, and remain updated on advancements.

[Sources: <u>1, 2</u>]