

## EXPERT [ACT]IVATION TIPS

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

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**[ACT]IVATION TIP:** "Encourage family members and friends to enlist on the national and international available donor registries. When a patient gets diagnosed with AML, everyone in their immediate circle wants to help, and I tend to see family members and friends offer their bone marrow for transplant purposes. The likelihood of a friend or a distant relative being a match is very low. Siblings may have a high chance of being a match, parents or kids may be a half-match by, so there's a higher chance of some unrelated person on the registry being a match to the patient than a distant relative or friend." - Dr. Sara Taveras Alam

**[ACT]IVATION TIP:** "Know that you are the decision maker. Doctors are there to guide the patient, to inform the patient. Definitely, there will be treatments that would not be recommended for a physician and they would not give, but generally, there's more than one possible right answer, and the patient should be empowered to decide what fits best for their lifestyle and what accommodations need to be made." - Dr. Sara Taveras Alam

**[ACT]IVATION TIP:** "...inquire if there are clinical trials available at the institution where you're being cared for, not all institutions do have clinical trials available, and that is okay, but you should be informed and given the opportunity to look into other facilities if clinical trials are available and have the ability to do so." - Dr. Sara Taveras Alam

**[ACT]IVATION TIP:** "...in terms of going out in the world, I would avoid for our AML patients to be in crowded spaces, and if they are going to be in crowded spaces to use a mask so that they're protected from respiratory infection." - Dr. Sara Taveras Alam

**[ACT]IVATION TIP:** "Voice your beliefs, so that your providers are aware of your goals and the barriers to care possibly and inform you better on how we can accommodate for your beliefs and improve upon the expectation that you may have from the healthcare system from previous experiences." - Dr. Sara Taveras Alam

**[ACT]IVATION TIP:** "Communicate with your providers if you have any barriers to care, things like transportation, things like cost of medication may not seem to a patient as though they are important to bring up to the provider, but it is really important to bring up these barriers, as there's things that may be done from the perspective of the hospital, perhaps they can connect you with financial assistance programs that may help with transportation, there's different societies that can help with that, some of the pharmaceutical companies can help with that too. mention whatever barrier you have to each person that is connecting with you from your healthcare team, social worker, medical assistant, nurse, doctor. The more people you mention it to, the higher the likelihood, that it will be taken care of." - Dr. Sara Taveras Alam

**[ACT]IVATION TIP:** "Take notes of conversations with your providers, include your caregivers, family members, and conversations about the care, bring them to visits. There is a lot to learn in the process of an AML patient. And it is all right to ask questions again and again. It is encouraged to ask questions until your understanding of what is going on and what the plan is. Patients really are their best advocates or should be their best advocate and should never assume." - Dr. Sara Taveras Alam

## BLACK AND LATINX AML PATIENT INFORMATION

- Black patients tend to present with AML at a younger age
- Black patients may be at a higher risk of complications during treatment than other patients
- Black patients have a higher risk of poor risk cytogenetics and a higher risk of not responding to treatment as well as a higher risk of complications from treatment
- Hispanic patients with comorbidities fared much worse than other populations with comorbidities
- Typically underrepresented in AML clinical trials

### Ways to Overcome

- Know your molecular and genetic characteristics to personalize your AML treatment
- Discuss with your healthcare team resources to help continue your care
- Patients can ask if their institutions offer clinical trials
- Replicate and expand trials to institutions beyond academic centers

## AML RESOURCES

- [Know-AML.com](#)
- [Cancer Support Community](#)
- [American Cancer Society](#)
- [The Leukemia & Lymphoma Society \(LLS\)](#)
- [Leukemia Research Foundation](#)
- [Be the Match](#)
- [National Comprehensive Cancer Network](#)
- [National Cancer Institute](#)
- [ASCO Cancer.net](#)
- [ACCC](#)
- [CancerCare](#)
- [Family Reach](#)
- [Triage Cancer](#)
- [Smart Patients](#)

## AML CARE CHECKLIST

- 1. **Understand your AML.** Know the genetic drivers of your disease and if medications or stem cell transplant can target those drivers.
- 2. **Schedule a meeting with your doctor.** Discuss diagnosis and treatment options with your oncologist.
- 3. **Establish your care team.** Find treatment centers experienced with treating AML with a individualized approach.
- 4. **Research treatment costs.** Understand insurance coverage and explore financial assistance options.
- 5. **Explore clinical trials.** Discuss your suitability with your doctor to weigh benefits and risks.
- 6. **Seek emotional support.** Talk openly with loved ones, consider talk therapy, and connect with relevant support groups.
- 7. **Maintain healthy lifestyle.** Discuss a plan with your care team that includes diet, exercise, and stress management.
- 8. **Stay informed.** Communicate regularly with your healthcare team, ask questions, and remain updated on advancements.

[Sources: 1, 2]