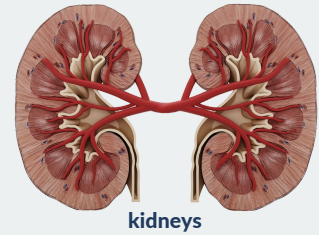


An [ACT]IVATED patient is informed, empowered, and engaged in their care.

- Get information about choosing a RMC specialist or treatment center
- Talk with family and friends about how you feel and how they can help you
- Find out what your insurance covers
- Get as much information as you can from reliable sources
- Talk openly with your doctor about your fears or concerns
- Determine if financial assistance is available



## RMC DIAGNOSIS

- Renal medullary carcinoma is easier to treat if diagnosed early.
- Young Black individuals (particularly those who are known to carry the sickle cell trait or sickle cell disease) should contact their healthcare provider if experiencing RMC symptoms.
- Most common symptoms are blood in the urine (hematuria), pain around the kidney, unintentional weight loss, fevers, or night sweats.
- An ultrasound of the kidneys is typically done and if a mass is found to be suspicious, a CT scan or MRI will be performed to confirm it is cancer. Your healthcare provider will take a biopsy of your kidney and test the tissue for the presence or absence of INI1 (also known as SMARCB1, hSNF5 or BAF47) using a method called "immunohistochemistry."

## RMC TREATMENT OPTIONS

- Treatment decisions are made by looking at disease stage, size of the RMC tumor, if RMC has spread to other areas of the body, an individual's age, general health, and other elements.
- Chemotherapy is often used as a first-line treatment.
- If CT or MRI imaging suggests that RMC is confined only to the kidney and has not spread to other areas, surgery might be considered to remove the whole kidney and the cancer inside it. If the RMC tumor is large, then doctors may decide to use chemotherapy first in order to shrink the tumor and to perform the surgery.
- Radiation therapy may also be used.
- Clinical Trials
  - Certain trials are looking at drugs that block the removal of unwanted proteins from cancer cells, drugs that target certain pathways, and drugs that harness the body's immune system to recognize and kill RMC cells
  - Be sure to ask your doctor if participating in a clinical trial could be right for you.

## RMC EXPERT TIPS

**[ACT]IVATION TIP:** "If an individual who has sickle cell trait sees blood in the urine, flank pain, chest pain, shortness of breath or weight loss, they need to contact their physician or go to a local emergency room to have an ultrasound or a CAT scan to really evaluate the kidneys." - Dr. Nizar Tannir

**[ACT]IVATION TIP:** "I tell my patients, this is an aggressive cancer, but we're in this together and there is hope and we have a plan. The prognosis is guarded, but there is a hope and I will give you a plan. Never ever give up. Get the facts, seek care at the hands of the experts, and we're here to help." - Dr. Nizar Tannir

**[ACT]IVATION TIP:** "Chemotherapy is good, but we hope to develop more effective therapies in the future. Please engage, enroll, participate in clinical trials only through research. We can advance the field and ultimately conquer this devastating disease." - Dr. Nizar Tannir

**[ACT]IVATION TIP:** "Do not panic at your diagnosis. Get medical facts from reliable resources. Get the rest you need, avoid strenuous and extreme exercise. Eat a healthy, well-balanced diet, stay hydrated, seek care at the best place you have access to, keep hope alive. There is hope." - Dr. Nizar Tannir

**[ACT]IVATION TIP:** "Patients with RMC now have a much better chance of surviving many years compared to years ago when they only had few months to live. Progress has been made, but there is more progress to achieve towards the cure. I am confident that we will conquer RMC in the future." - Dr. Nizar Tannir

## RMC FACTS

- RMC is a rare cancer of the kidney that mainly afflicts young people of African descent who carry the sickle cell trait.
- RMC is twice more likely to occur in men than women, and in the right kidney compared with the left kidney.

## RMC RESOURCES

- [ACCC](#)
- [CancerCare](#)
- [Cancer Grace](#)
- [Family Reach](#)
- [Triage Cancer](#)
- [Cancer Support Community](#)
- [RMC Support](#)
- [RMC Alliance](#)
- [Ryse Up Now](#)