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ISM Care: Best Practices for Taking a Multidisciplinary Approach

### Announcer:

You're listening to *Project Oncology* on ReachMD, and this episode is sponsored by Blueprint Medicines. Here's your host, Dr. Charles Turck.

### Dr. Turck:

Welcome to *Project Oncology* on ReachMD. I'm Dr. Charles Turck, and joining me to explore best practices in the multidisciplinary care of patients with indolent systemic mastocytosis, or ISM for short, are Drs. Cem Akin and Anthony Hunter. Dr. Akin is a Clinical Professor specializing in Allergy, Immunology, and Internal Medicine at the University of Michigan. Dr. Akin, thanks for being here today.

### Dr. Akin:

Thank you, Dr. Turck. Glad to be here.

### Dr. Turck:

And Dr. Hunter is an Assistant Professor in the Department of Hematology and Medical Oncology at Emory University School of Medicine in Atlanta. Dr. Hunter, it's great to have you with us as well.

### Dr. Hunter:

Absolutely. Thank you for having me today. I'm excited to be here.

### Dr. Turck:

So starting with you, Dr. Hunter, would you tell us about the specialists who are typically part of the ISM care team?

### Dr. Hunter:

Yes, absolutely. This is something that you'll hear me talk a lot about when I talk about ISM, about needing individualized approach based on the patient, of their presenting features, what's available, and what kind of treatments they're getting. This holds true for the treatment team as well. I think this varies from patient to patient and what they may actually need as part of their care team. An unfortunate part of this in the real world in America is that there's not a lot of expertise sometimes in this disease, and so there are sometimes limitations to what's actually available to be part of that care team. So in a perfect world, I think this is a disease that should be co-managed by hematologists like myself as well as an allergist like Dr. Akin. I think both of us bring very unique perspectives to the table. We have different sort of aspects to how we think about this disease. Now which one takes a little bit more of a central role can vary from patient to patient based on what they need and which providers may be more available to them from a location standpoint or availability. So I think having both of those specialists as a part of the care team is really important in a perfect world.

Now beyond that, there may be additional physicians and specialties that need to be part of the care team for patients. So certainly, skin and cutaneous symptoms can be a big part of this disease for some patients. So having a good dermatologist who can provide additional aspects to treatment, doing biopsies, etc., for patients can be a key portion, at least for some patients. A number of patients with ISM have a lot of GI symptoms, and so having a good gastroenterologist as part of the care team who can provide endoscopy services, do GI biopsies, and help with managing GI symptoms can be important. I'll add that we do see an increase in anxiety and depression in ISM, so having a psychiatrist or a mental health professional who can be available to these patients can be a key part of the team as well. And then certainly, additional ancillary services can be great beyond that. Not everyone has that certainly. I'm blessed to be part of a very large cancer center, so I have great social workers and a great pharmacy team. We have nutritionists and things that can certainly be added benefits for some patients as well.

**Dr. Turck:**

And let's turn to you now, Dr. Akin. When should patients with ISM be referred to specialists like yourself?

**Dr. Akin:**

Good question. As an allergist and immunologist, I think that all patients diagnosed with non-advanced or indolent systemic mastocytosis should be referred to an allergist/immunologist because these patients present primarily with symptoms of mast cell activation and symptoms that you might expect to get an allergic reaction or anaphylaxis, and there's really no other specialist who is more informed or educated to take care of these symptoms than allergists and immunologists. An allergist can also prepare specific care plans for upcoming procedures or surgeries for these patients, and he or she can evaluate coexisting allergies, such as venom allergy, which could be a significant life-threatening problem in a subset of our patients with mastocytosis. And they can also act as a general resource for their PCPs and other consultants.

**Dr. Turck:**

For those just tuning in, you're listening to *Project Oncology* on ReachMD. I'm Dr. Charles Turck, and I'm speaking to Drs. Cem Akin and Anthony Hunter about best practices for interdisciplinary collaboration when caring for patients with indolent systemic mastocytosis, or ISM.

Now if we come back to you, Dr. Hunter, how do you and the team monitor patients once you put a care plan into effect?

**Dr. Hunter:**

There's no one-size-fits-all approach for different patients here, right? We have patients who really exist on a broad spectrum of disease with ISM that we see in clinical practice. So I have patients who really suffer day-to-day with symptoms that really dramatically affect quality of life and needs various types of therapy to impact that. On the other end of that spectrum, I have patients who were diagnosed based on, say, one anaphylactic event a year and a half ago but really don't have any ongoing symptoms, and so they need a lot less monitoring and ongoing care than my patient who has really daily symptoms.

And so there's a big spectrum of what we see patients present to us and how we might monitor those patients. My patients who are really minimally symptomatic, maybe they're on one antihistamine a day; that's a patient I may see once a year in my practice, right? Just to monitor to make sure they're doing okay and not having emerging symptoms.

ISM is an indolent disease, thankfully, but there is a small risk that it can progress to more advanced systemic mastocytosis and that patients can develop myeloid neoplasms associated with SM. And so we do need ongoing monitoring for that. And so at a minimum, I'm monitoring my patients annually with a complete blood count to monitor for cytopenias or changes in their blood counts and chemistry panels to look at their hepatic and renal function to monitor for any organ damage. And also, I'm typically monitoring tryptase as a biomarker, one of the easiest accessible or available tests that we have as sort of a simple biomarker to monitor sort of mast cell burden, so to speak, in this disease. And so those are ongoing lab monitoring that we want to do, again, at least on an annual basis. Sometimes more frequently than that. A lot of my patients do come and see me twice a year or every 6 months.

On the other end, though, I do have some of these patients that are very symptomatic, right? And so some of those patients are going to be on a lot more longer lists of therapies. We're going to need to monitor more closely for side effects, titrate the doses of those medications, and see if we need to change medications at all. We're also starting to use more tyrosine kinase inhibitor, or TKI, therapies, KIT inhibitors in mastocytosis, so that may require a little bit closer monitoring for side effects as well as response to those treatments.

Another impact for this and how I monitor depends on that care team that's been assembled for a patient, right? So if they have a great allergist, maybe one who's closer to home for them or this patient really has more symptoms that can be really effectively managed by an allergist, I might not see them quite as much in my hematology practice, and I let that allergist take a little bit more of a central role in the therapy but still help with that monitoring and assessing need for therapies as well.

**Dr. Turck:**

And if we focus on another aspect of multidisciplinary care, Dr. Akin, would you share some best practices for communicating with the care team throughout the patient's journey?

**Dr. Akin:**

Sure. I think in this day and age where electronic records are the standard of care, I think all patients, if possible, should have access to their electronic records, print them out, and bring it to the other consultants or practitioners when they see somebody who is not familiar with mastocytosis. And most of the time, it is the case that a new practitioner is not familiar with mastocytosis. It is a rare disorder, so it can be very helpful to have the evaluation records, office notes, and lab results from the mastocytosis specialist the patient has seen

before.

It is also very important to document the allergies that the patient may have experienced, especially drug allergies and intolerances, because while the risk or prevalence of drug allergy does not seem to be necessarily higher than general population in mastocytosis, if they do have a drug allergy, the manifestation of that allergy could be more severe and anaphylactic and could even be life threatening. So it is very important to have this portable documentation of drug allergies, especially if the patient is seen in a different healthcare system. Likewise, the mastocytosis specialist may not be in the same health system as the patient's primary care doctor or the patient might be visiting the specialist from out of state. So in that case, some tests that might be ordered by the mastocytosis specialist may not be immediately available to the ordering doctor because they are in different health systems. So in that case, it should be made clear that the test should be communicated to the ordering doctor, and that also includes the emergency room tests such as tryptase levels. We sometimes see a reluctance on the part of the emergency room providers to obtain necessary testing like tryptase levels because they may not be able to follow up on it. But if there is a prescription for that laboratory test with the fax number and clear instructions on how to communicate that test result to the ordering physician, that might relieve the anxiety on the part of the other physicians.

**Dr. Turck:**

And before we close, Dr. Hunter, what kind of impact can a team-based approach have on the outcomes of patients with ISM?

**Dr. Hunter:**

Certainly, we have different perspectives; we have different experiences. We've got different strengths that we have. I think beyond that, sometimes testing availability and what we have in our practice varies, right? As a hematologist, it's very, very easy for me to get a bone marrow biopsy and to do molecular testing, something we do on a day-to-day basis in our practice that may not always be quite as easy to do in allergy practice. I may not have quite as much access to some of those things, and so, there are different resources, testing, and things that may be more available at one site or one specialty practice versus another.

I think in addition, we've sort of gotten to the fact that it can be a little bit hard to find adequate care/expertise in this disease, right? And so I see patients from all over the Southeast, and those patients don't necessarily want to come drive to see me in Atlanta every month or two if they live four hours away, right? But maybe they come see me once a year and have an allergist who lives or practices much closer to them that can provide some of that care in the interim. And so even just that aspect of logistics can be impactful for patients as well. So I think we all work better when we work in teams and we have multiple sets of eyes to sort of look at or think about a problem and sort of bring different perspectives to the table to help really adequately treat patients with this really unique disease.

**Dr. Turck:**

Well, with that potential impact in mind, I want to thank my guests, Drs. Cem Akin and Anthony Hunter, for joining me to discuss how we can best take a multidisciplinary approach when caring for patients with indolent systemic mastocytosis. Dr. Akin, Dr. Hunter, it was great having you both on the program.

**Dr. Akin:**

Great to be here. Thank you, Dr. Turck.

**Dr. Hunter:**

Absolutely. It was a pleasure to be here and thank you for having me.

**Announcer:**

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