

# More to “Indolent”

Uncovering the potential impact of indolent systemic mastocytosis (ISM) beyond the symptoms

**indolent**<sup>1</sup> in·do·lent

adjective

a: causing little or no pain

b: slow to develop or heal

A resource for healthcare providers

*The patients quoted in this brochure are adults with ISM who are compensated speakers for the Blueprint Medicines Ambassador program. Individual experiences will vary.*





## WHAT YOU MAY SEE...

### ...is that the symptoms of ISM can be unpredictable and potentially severe<sup>2-4</sup>

ISM is a clonal mast cell disorder associated with the uncontrolled proliferation and activation of mast cells. Symptoms of ISM can manifest across **multiple organ systems**, including systemic, gastrointestinal, musculoskeletal, skin, and neurocognitive. Symptoms can be **unpredictable and potentially severe**, and they **may mimic other disorders and conditions**.<sup>2-4</sup>

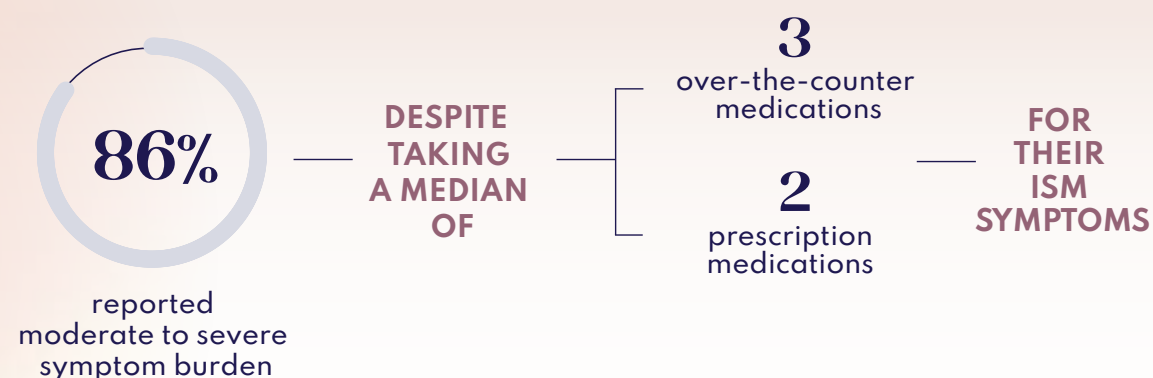
Symptoms of ISM can be **triggered by aspects of everyday life**, including heat, stress, exercise, and food.<sup>3,5</sup>

**"I am filled with fear about eating. I am filled with fear about going to sleep. I am filled with fear about being alone."**

Kristine, a patient describing living with ISM

### Despite taking multiple symptom-directed therapies, patients reported living with moderate to severe symptom burden<sup>7\*</sup>

In a Blueprint Medicines-sponsored patient-reported survey, of patients with ISM (n=37)<sup>7\*</sup>:



**"I've taken many different medications, and found that my symptoms just weren't resolved."**

Teri, a patient describing living with ISM



## WHAT YOU MAY NOT SEE...

### ...is that the symptom burden of ISM can have significant impact on daily life<sup>2,7\*</sup>

### Patients with ISM report that the disease and its symptoms affect both their personal and work lives<sup>7\*</sup>

In the Blueprint Medicines-sponsored patient survey, of 32 patients with moderate to severe ISM symptom burden, **56% reported reducing work hours because of their ISM**, and **72% reported avoiding leaving home because of their ISM symptoms**.<sup>7\*</sup>

**"I tend to isolate when I have more symptoms. I stay in a lot, and it can feel depressing."**

Teri, a patient describing living with ISM

### In 2 quality-of-life surveys of patients with ISM (N=164)<sup>6†</sup>:

#### PSYCHOLOGICAL

**60%**

Reported **feelings of depression and somberness**

#### SOCIAL

**69%**

Reported that their **social lives had suffered** due to the disease

#### EMOTIONAL

**59%**

Reported that **fatigue** had an influence on their **happiness**

#### ENVIRONMENTAL

**67%**

Reported **feeling embarrassed** because of their skin abnormalities

#### COGNITIVE

**70%**

Reported **fear of falling** and incurring fractures

**70%**

Reported **impaired short-term memory**

**"For me, it's about control. If I feel that I have control over my symptoms, I feel much better about what's going on in my life."**

Kristine, a patient describing living with ISM

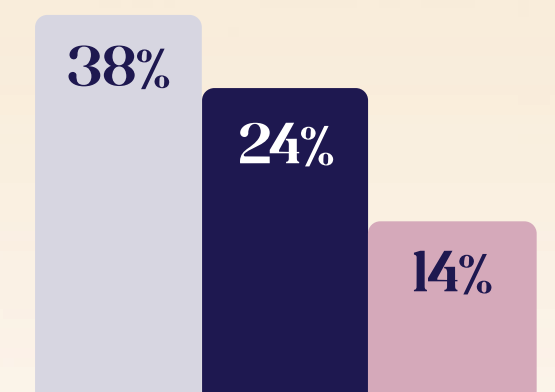
<sup>\*</sup>In the Blueprint Medicines-sponsored TouchStone SM Patient Survey, 56 US adults with a self-reported SM diagnosis completed a 100-item survey. An unpublished analysis of a subset of those patients with ISM (N=37), including 32 with moderate to severe ISM symptoms (defined as an ISM-SAF TSS ≥28), was conducted.<sup>7</sup>

ISM-SAF=Indolent Systemic Mastocytosis-Symptom Assessment Form; SM=systemic mastocytosis; TSS=total symptom score.

<sup>†</sup>Data from a Dutch validation study of 2 patient-reported outcome measures of quality of life and symptom burden in 164 patients with ISM. Patients completed a 49-item mastocytosis QoL questionnaire (MQLQ) asking patients to rate the burden of ISM symptoms on their daily life and the mastocytosis symptom assessment form (MSAF) asking patients to rate the severity of their ISM symptoms and the influence of fatigue on specific categories (eg, mood/temper, chores, happiness) over the past 24 hours.<sup>6</sup>

# Why you may not be hearing the whole story

In the Blueprint Medicines–sponsored survey, of 37 patients with ISM<sup>9,†</sup>:



- Discuss symptoms with their HCP only when they feel really bad
- Feel they are burdening their HCP when discussing how they are feeling
- Report they don't feel comfortable discussing all their symptoms with their HCP

## Some additional questions to consider asking patients<sup>6,8</sup>

- What activities have you reduced or stopped doing because of ISM?
- What adjustments have you made in your daily life to manage ISM?
- Does ISM impact how you perform daily activities and work?
- How is ISM affecting the lives of you and your family?

**“It’s all about the relationship and trusting each other—the doctor and the patient—knowing that you are a team; otherwise, the patient may hold back.”**

**Kristine, a patient describing living with ISM**

**Want to learn more about managing ISM?**

**Visit [IndolentSM.com](https://www.IndolentSM.com)**



<sup>†</sup>In the Blueprint Medicines–sponsored TouchStone SM Patient Survey, 56 US adults with a self-reported SM diagnosis completed a 100-item survey. An unpublished analysis of a subset of those patients with ISM (N=37), including 32 with moderate to severe ISM symptoms (defined as an ISM-SAF TSS  $\geq 28$ ), was conducted.<sup>9</sup>

HCP=healthcare provider.

**References:** **1.** Merriam-Webster.com. Indolent. Accessed February 9, 2024. <https://www.merriam-webster.com/dictionary/indolent> **2.** Pardanani A. *Am J Hematol*. 2023;98(7):1097-1116. **3.** Gülen T et al. *J Intern Med*. 2016;279(3):211-228. **4.** Theoharides TC et al. *N Engl J Med*. 2015;373(2):163-172. **5.** Jennings SV et al. *Immunol Allergy Clin North Am*. 2018;38(3):505-525. **6.** van Anrooij B et al. *Allergy*. 2016;71(11):1585-1593. **7.** Data on file. Blueprint Medicines Corporation, Cambridge, MA. 2023. **8.** Mesa RA et al. *Cancer*. 2022;128(20):3691-3699. **9.** Data on file. Blueprint Medicines Corporation, Cambridge, MA. 2024.



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