

# EXTERNALLY LED PATIENT-FOCUSED DRUG DEVELOPMENT MEETING

31 OCTOBER 2023

**PRESENTATION**

**Living With hEDS/HSD and MCAS**

**SPEAKER**

**Courtney Rabb**  
**Patient Advocate**



# CONFLICTS/DISCLOSURES

I have no conflicts of interest

Disclosures: I write a non-monetized blog sharing my journey called a “A Rare Normal”

## Officially Diagnosed- 6 months pregnant





## Navigating Life in a World Full Of Triggers



### MAST CELL DISEASE COMMON TRIGGERS

These generalized triggers are common, but each patient has their own specific sensitivities.  
*not just a picnic in the park*

Reactions are often **disabling and dangerous.**

**Stress** Physical, emotional and environmental stress are all major triggers, as is fatigue. Unpredictable symptoms can make living with mast cell disease very challenging!

**Medication** Get a headache? Careful! Certain medications can be triggering.

**Specific Foods**

**Alcohol**

**Odors**

**Insect Stings & Bites**

**HOT OR COLD**  
Temperatures

**Exercise**  
Even modest exercise can be triggering for some.

**And more!**  
Patients can react to a wide range of triggers! <sup>1</sup>

LEARN MORE AT [tmsforacure.org](https://tmsforacure.org)

<sup>1</sup> Jennings S, et al. J Allergy Clin Immunol Pract. 2014;2(1):70-6.

The illustration shows a white stick figure walking on a green path. To the left, there are pine trees and a campfire. To the right, there is a picnic table with a cake, a bottle of alcohol, and a glass. A bug is shown stinging the person. Various text boxes are connected to the scene by lines, indicating different triggers like 'Hot or Cold Temperatures', 'Odors', 'Insect Stings & Bites', 'Specific Foods', 'Alcohol', 'Exercise', 'Stress', 'Medication', and 'And more!'. A 'BUG' icon is also present near the picnic table.

## A Family Affair- Rare Disease Day 2020





## My Heroes





**Thank you for  
your attention**