



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.

Insect Stings & Bites

Specific Foods

Alcohol

Odors

Temperatures HOT or COLD

Exercise Even modest exercise can be triggering for some.

And more! Patients can react to a wide range of triggers!

LEARN MORE AT tmsforacure.org

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

A Family Affair- Rare Disease Day 2020



My Heroes





**Thank you for
your attention**