

EXTERNALLY LED PATIENT-FOCUSED DRUG DEVELOPMENT MEETING

31 OCTOBER 2023

PRESENTATION

**Living with EDS and Mast Cell
Activation Syndrome**

SPEAKER

Danielle Vaccaro.
Exercise Physiologist, RYT 200, Graduate of
Jeannie di Bon's Integral Movement Method.



My Early Symptoms



- Diagnosed in May of 2021 at 27 years old
- 1st symptoms began in elementary school
- 2012 began Undergrad studying Exercise Physiology
- 200 Hr Yoga Teacher Training in 2016



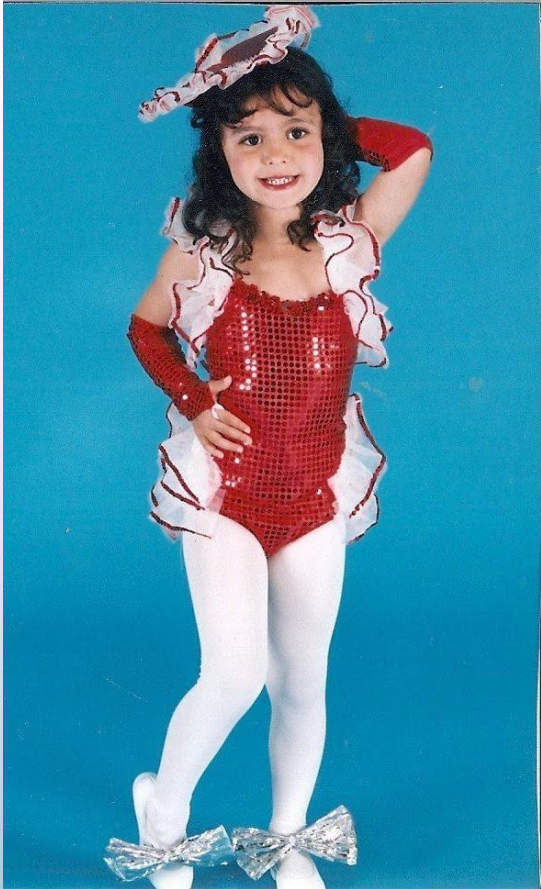
My First Time feeling Validated



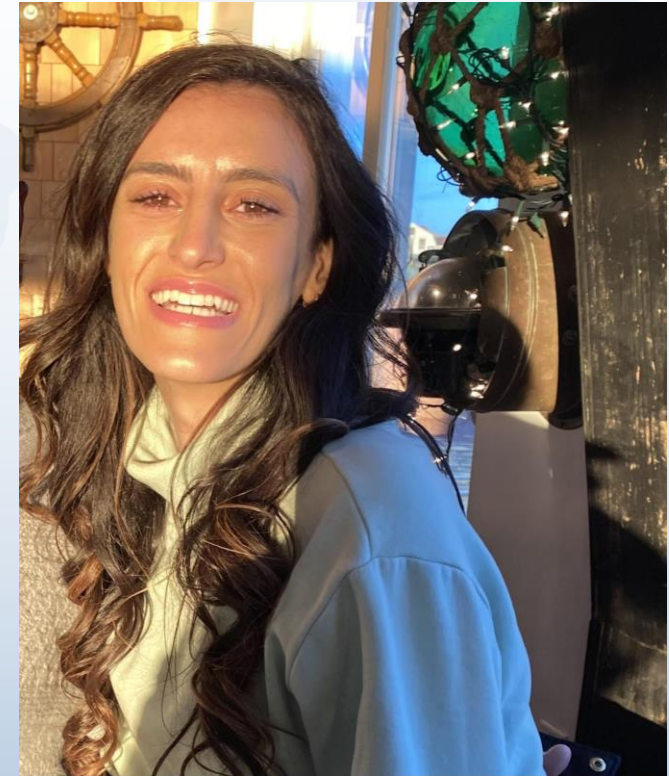
- Debilitating pelvic pain, menstrual cycles, heavy bleeding, urinary & bowel symptoms, etc
- February 4th of 2021- Laparoscopy Exicision Surgery for Endometriosis.
- Abnormal recovery - high stress event exacerbated other already present symptoms



Official Diagnosis of Ehlers-Danlos Syndrome



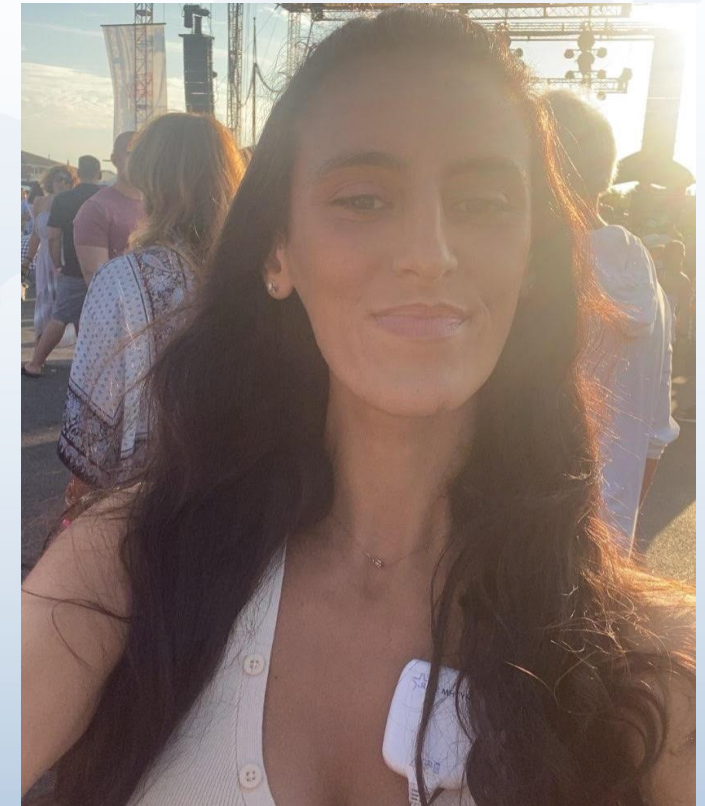
- Finally felt heard and validated in May of 2021
- Overwhelming journey of research and self-advocacy
- Not yet educated about the possible co-morbidities– not yet aware makeup reactions were related to histamine issues
- Specialist first mention of Anaphylaxis



Other Diagnoses in addition to Ehlers-Danlos Syndrome



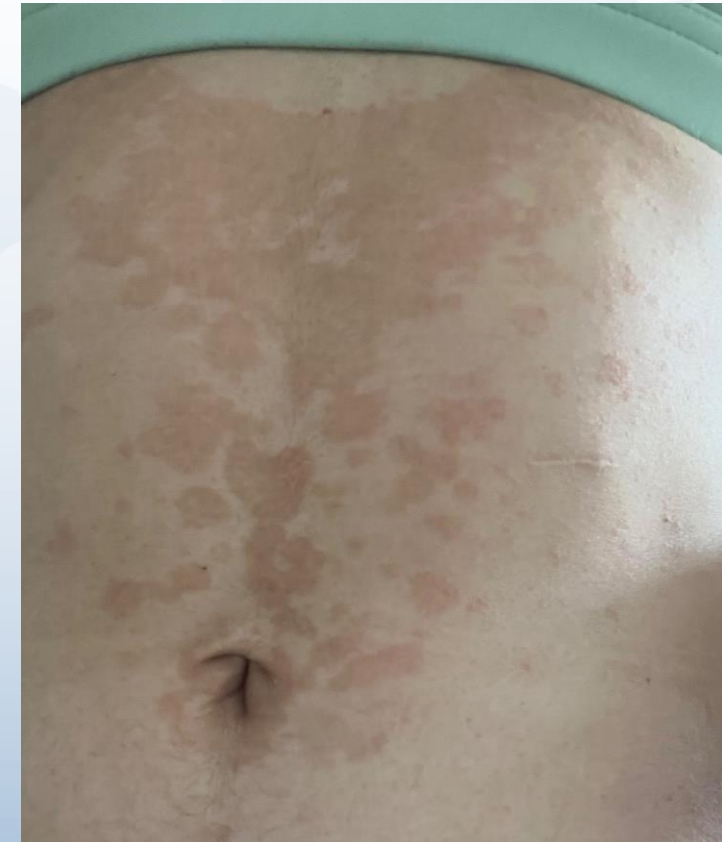
- Endometriosis
- Dysautonomia
- Small Fiber Neuropathy
- Anemias
- Occult Tethered Cord Syndrome
- Mast Cell Activation Syndrome



My Skin as a result of Mast Cell Activation Syndrome



- Skin rashes and reactions
- Sensitivities to makeup and many other products
- Slowly switching to low toxic products
- Antihistamines and H2 blockers with some relief, but seeing a specialist in Feb of 2024



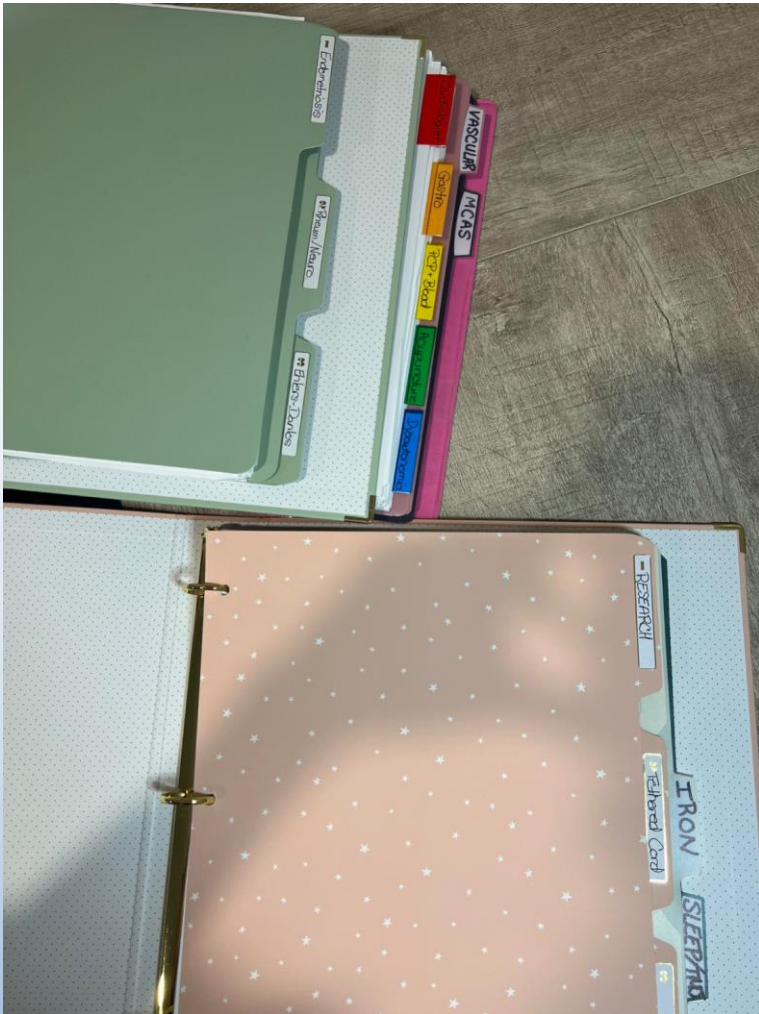
MCAS Flares



- Urgent cares and Emergency Department visits
- ENT & Allergy/Immunologist visits
- Endless tests and monitors to access throat closing, esophagus issues, swallowing difficulties, etc.



YOU are your very OWN BEST Advocate!



- Despite your mast cell blood work results being “normal”, what you are experiencing is REAL
- Unfortunately, with MCAS, bloodwork isn’t always 100% accurate
- You know your body best. You are NOT alone!
- There must be more education and advocacy to help spread awareness



**Thank you for
your attention**