



## UNC ALLERGY MAST CELL DISORDERS PROGRAM: AN AIM REFERENCE CENTER

To Whom It May Concern:

Thank you for your interest in the UNC Allergy & Immunology Mast Cell Disorders Program for your care needs. Unfortunately, UNC Allergy & Immunology is temporarily unable to evaluate any new patients concerned for mast cell activation disorders (MCAD, MCAS, mast cell activation). We currently lack the capacity to provide care for any additional patients, and **we cannot accept any new referrals at this time.**

Below, **you will find information that you can give to your primary care provider (PCP)** to start the diagnostic testing process and initial symptom management.

1. Describe in detail to your referring provider or PCP whether you have ever experienced anaphylaxis without any known trigger. Report whether you experience symptoms involving the skin, gastrointestinal tract, cardiovascular and respiratory systems. Please see the table from the American Academy of Allergy, Asthma, and Immunology (page 4) for a list of organ systems and associated symptoms that are helpful for the diagnosis of mast cell activation.
2. Ask your referring provider or PCP to send the following lab testing:

Note: we have listed a few commercial labs where these tests can be sent, if your provider cannot send them through their hospital system or practice network:

### **Labs to collect at your convenience:**

\_\_\_ **Alpha-gal Panel** (LabCorp: 807003); (Mayo: FAGPL)

Note: includes AG IgE, Beef IgE, Lamb IgE, Pork IgE

\_\_\_ **Total IgE** (LabCorp: 002170); (Mayo: IGE); (can also be ordered through Quest)

\_\_\_ **Tryptase**, serum (LabCorp: 004280) (Mayo: TRYPT) when you are feeling stable, with minimal symptoms

### **Labs to collect when you are having a symptom flare:**

\_\_\_ **Tryptase**, serum (LabCorp: 004280) (Mayo: TRYPT) within 4 hours of when you are having a symptom flare

\_\_\_ **Serum PGD2** (prostaglandin D2) (Mayo FD2PG)

If possible, Patient should NOT be on any aspirin, indomethacin, or anti-inflammatory medications for at least 48 hours prior to collection of specimen for serum PGD2 testing.

\_\_\_ **24-hour urine, N-methylhistamine** (Mayo: NMH24); (Quest Diagnostics: 39559); (ARUP: 2011034); (LabCorp: Order Name N-METHYLHI; Test Number: 3811100)

\_\_\_ **24-hour urine leukotriene E4** (Mayo: TLTE4); (Quest Diagnostics: 11976); (ARUP: 3004792); (LabCorp: Order using New Test Misc: Use Labcorp test number 831775);

\_\_\_ **24-hour urine, 2,3-Dinor 11 Beta-Prostaglandin F2 Alpha** (Mayo: 23BPT); (ARUP: 3002337); (Quest 10041); (Labcorp Order Name 2,3Dinor-11b, Test Number 6907123)

Patient should NOT be on any aspirin, indomethacin, or anti-inflammatory medications, if possible, for at least 72 hours prior to collection of specimen for 24-hour urine 2,3-Dinor 11 Beta-prostaglandin F2 Alpha.

**24 hour urine samples must be kept in the refrigerator or on ice when you are not actively collecting sample to increase the accuracy of the testing.**

3. Therapeutic options to try: (prescriptions, compounded, over-the-counter supplements, and vitamins) that can be helpful for treating mast cell activation symptoms include:

- **Non-drowsy (2<sup>nd</sup> generation) H1 Anti-histamines** : (including cetirizine [Zyrtec], fexofenadine [Allegra], levocetirizine [Xyzal], loratadine [Claritin], desloratadine [Clarinox] – For most patients, it is safe to take up to four times (4X) the recommended over the counter dose.
- **Drowsy (first generation) H1 antihistamines:** (diphenhydramine [Benadryl] as needed for acute symptoms not fully controlled by taking non-drowsy H1 antihistamines on a regular basis; chlorpheniramine [ChlorTabs])
- **Prescription (1<sup>st</sup> generation) H1 antihistamines:** (examples include hydroxyzine, low dose doxepin, and cyproheptadine)
- **H2 antihistamines** (Famotidine [Pepcid] is preferred to cimetidine [Tagamet], since cimetidine can interact with many other medications).
- **Mast Cell Stabilizers:** (over the counter cromolyn nose spray; prescription oral cromolyn; prescription nebulized cromolyn; over the counter ketotifen eyedrops; compounded prescription strength ketotifen capsules)
- **Leukotriene Pathway Blockers:** (Montelukast [Singulair], Zafirleukast; Zileuton)
- **Natural Supplements:** Over the counter: Vitamin C, Quercetin, Diamine Oxidase
- **Epinephrine autoinjector to treat anaphylaxis** (Epipen, Auvi-Q, Adrenaclick, etc.)

- **Consider cognitive behavioral therapy / dynamic neural retraining techniques** to help with managing the stress, anxiety surrounding adverse reactions to foods and other triggers
4. Please visit these websites to find additional **academic medical centers, regionally and nationally**, with special interest in management of mast cell diseases:
- a. The Mast Cell Disease Society: <https://tmsforacure.org/>
  - b. The American Initiative in Mast Cell Diseases: <https://aimcd.net/>
  - c. Your community allergist / immunologist can also initiate diagnostic testing and recommend alternative centers for evaluation for mast cell activation disorder.
5. Please visit this website (<https://tmsforacure.org/>) to find helpful medical documentation, including:
- a. **Surgical pre-treatment protocols** to reduce the risk of mast cell activation and/or the severity of mast cell activation symptoms during and immediately after surgery
  - b. **Documentation to give to Emergency Room Providers on** how to treat you during a severe flare / anaphylaxis

We hope to re-open our Mast Cell Disorders Program to new patients in the future, but we do not have a confirmed re-opening date at this time. We thank you for your patience and understanding.

Sincerely,

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On Behalf of the  
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**TABLE II.** Organ systems affected during anaphylaxis and associated symptoms of their involvement that are of diagnostic value for MCAS

|  |  |
|--|--|
| Cardiovascular                               | Respiratory                                      |
| Hypotension                                  | Wheezing (inspiratory or expiratory)             |
| Tachycardia                                  | Shortness of breath                              |
| Syncope or near syncope <sup>6,7,30,32</sup> | Inspiratory stridor <sup>6,7</sup>               |
| Dermatologic                                 | Gastrointestinal                                 |
| Flushing                                     | Diarrhea   |
| Urticaria <sup>6,7,30,32,34</sup>            | Nausea with vomiting                             |
| Pruritus                                     | Crampy abdominal pain <sup>6,7,10,28,30,32</sup> |
| Angioedema <sup>6</sup>                      |  |

As recommended for the working diagnosis of systemic anaphylaxis, symptoms affecting at least 2 of these 4 organ systems should occur concurrently.<sup>33</sup>