Visit TMSForACure.org or send us an email at info@tmsforacure.org for more!

Follow us to stay up to date:

@TMSforacure www.linkedin.com/company/tmsforacure/ @MCDiseasesUnite

As an organization who predominantly serves vulnerable populations, we are committed to modeling diversity and inclusion for the entire community whatever their gender, race, ethnicity, national origin, age, sexual orientation or identity, education or disability, and to maintaining an inclusive environment with equitable treatment for all. We respect and value diverse life experiences and heritages and ensure that all voices are valued and heard.

This patient resource guide in no way seeks to serve as a substitute for professional medical care. These resources are a work in progress that may be redefined as often as new significant research become available. Consult your doctor before undertaking any form of medical treatment or adopting any exercise program or dietary guidelines.
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## SECTION II: Emergency Room Response Plan

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- Helpful Links  
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Section I

Patient Advocacy, Disability, and Daily Life
Name

Date of Birth

Home Address

Height

Weight Range

Medic Alert Jewelry Phone Number

Phone Numbers:

Home

Cell

Work

Primary Care Physician Name & Address

In Case of Emergency, Please Contact (Name & Phone Number)

Current Diagnoses:


Physician Signature

Date
Current Medications:

____________________________________________________

____________________________________________________

____________________________________________________

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Allergies:

____________________________________________________

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____________________________________________________
TMS does not advocate for any specific diet, even “low histamine”, as they can lead to deficiencies.

**Food intolerance testing** - there is no scientific backing to it and causes you to eliminate nutritional foods completely.

**IN ORDER TO BE HEALTHY, YOU NEED VARIETY!**
- Try something new! Don’t get locked into the same foods all the time.
- It’s all about trial and error.
- Sometimes you can have certain foods, while other times you may not. It’s not black and white.
- Avoid pre-made mixtures, and approach processed foods with caution – if you see a product that looks good, reproduce it at home!
- Fresh meat only – no leftovers, buy from a reputable butcher and freeze at home.
- Don’t look for perfection - manage the nuisances, and eliminate allergic triggers.

**If in anaphylaxis, TREAT SERIOUSLY! Use your Anaphylaxis Action Plan**

**SUBSTITUTION LIST OF MOST COMMON FOOD ALLERGIES**
- Tomatoes ➔ roasted peppers
- Peanuts & nuts ➔ chickpeas, seeds, seed butter
- Milk ➔ coconut, almond, soy, rice
- Egg ➔ applesauce, bananas, chai seed
- Shellfish ➔ lean proteins or mushrooms
- Soy ➔ coconut aminos or quinoa

**FOOD GROUP DIETARY RECOMMENDATIONS**
The image on the right is an example of recommended portions of each food group from the USDA. To find your estimated proportions, please visit:
https://www.myplate.gov/eat-healthy/food-group-gallery

**ADDRESS SUPPLEMENTS**
- Guidelines on what to look for if taking supplements
- Meant to supplement your diet, not replace the balance of a variety of foods
- Having too much of a good thing can be bad
- Always discuss possible interactions with your doctor before adding to your regimen
  - Interaction of supplement with other supplements
  - Interaction of supplement with foods
  - Interaction of supplement with medications

**HOW TO KNOW IF A WEBSITE IS REPUTABLE**
- Check the sources! Do they cite their sources, or are they writing their own opinions without backing up facts?
- Check the domain name, do your research to decide if they are reliable.
- Is there bias?
- Trust your gut.
- Who’s the author? Check their background.
# Food Journal

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**Notes:**

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__________________________________________________________________________
Steps to Making the Most Out of an Office Visit

You have been waiting for this appointment for months, and you are anxious to get there and have all of your questions answered. You wonder if you will like this physician or if you have finally found someone who understands the complexities of mast cell disorders. You wonder, how can I best prepare for this appointment so that I make the most of it?

Even if this is a return visit, preparing can help you make the most of it!

STEP 1:
Before the day even arrives, you need to begin preparations.

• Type, save, and print a sheet with your name, address, phone number, email, all current diagnoses, and all current allergies.
• Next to each allergy, state what happens to you if you take the drug or food (i.e., penicillin- anaphylaxis; amlodipine- hives). Keep this and other lists in your computer and update regularly.
• Before each appointment, check to make sure all information is up to date.

STEP 2:
On another sheet, list all of your medications by indications. The template for this can be found in the TMS ER Protocol: www.tmsforacure.org/ER (pages 4-7). You can print this out and fill it in. This will help the physician see and understand what medications you are currently taking, and why you are taking them.

STEP 3:
On a third sheet, list all of your physicians, starting with your primary care physician, and specialists, including their addresses, phone numbers, and emails if you have them. This will be extremely useful so that the physicians can communicate with each other by sending notes about your visit to other specialists on the list per your request.

STEP 4:
The fourth list is for your personal use during the appointment. Make a list of your chief concern for this visit, and list specific questions you have. Post this list on your refrigerator, and add to it as you think of things you would like to ask in the days leading up to the visit.

GOOD WORK!

Now, see if you can get a spouse, caregiver, or good friend to go with you. A second set of ears is always helpful. Ask that person to take notes so you can concentrate on listening to the doctor.

You are on your way! The big day has arrived. You have done your prep work, and you want to be heard. However, the reality is that patients are allowed to finish their opening statements less than 23% of the time according to a study in the Annals of Internal Medicine.
SO HOW CAN YOU BE HEARD ONCE YOU ARRIVE?

First of all, understand that you have 15 minutes or less for this entire appointment. Seriously! Start out by greeting your physician warmly and connecting with him/her on a human level in some way: “Wow, thank you for seeing me. I can see how busy you are today!” This compassion expressed for your physician may make your physician more likely to feel compassion for you! Now that the greeting is over, get down to business. The clock is ticking...

1. State the **reason for your visit** and that you have a **list of specific questions** that you need to have answered. This allows you to set the pace for the visit.
2. When giving your history, **be concise and to the point**. Not, “I started out as a preemie”, but instead, “I have MCAS, and was diagnosed at age 34. I am also a diabetic on insulin and have POTS.” If this is a repeat visit, state the reason for it: “I have been having pain in my abdomen over the past three months.”
3. When the physician asks you a question, stop paying attention to your list. **Make eye contact and answer the doctor!** You want him or her to know you are engaged in the visit!

**DID YOU KNOW?**

Most physicians are expected to see at least one, if not two, patients every 15 minutes. This is a tremendous amount of pressure on even the best, most compassionate physician.

One of the most difficult parts of being a patient with a chronic illness is trying to be objective while describing the misery you experience on a daily basis. In a physician visit, it makes a big difference if you can describe your symptoms objectively. Physicians turn off if patients vaguely describe pain, for example, as “it was the most excruciating pain I have ever had, it was like knives going through my back”. Alternatively, try a more objective approach: “I had pain in my upper right abdomen over the last month and it radiates to here (point to spot). I feel nauseated with the pain. It varies from 6-8 on the pain scale of 10. One night it woke me up and was 9 out of 10.”

Sometimes, it seems like the physician may not be asking the right questions or does not seem to be understanding your problem. In this case, concisely expand your narrative to redirect him or her: “The pain is right here, and it gets worse 1-2 hours after eating, when it becomes 8 on the pain scale. It had woken me up at night. What could this be?”

If you are lost, and do not understand what the physician is saying, say, “Wait, please. I am lost. Please slow down and explain again.” It is important to recognize that this is no reflection of how smart you are or how good or bad of a teacher the physician is, but rather, is almost always a result of time stressors on the physician. However, you are paying for this visit, so respectfully ask for appropriate care. If the doctor asks you a questions that seems bizarre, unrelated to your illness, or is just plain confusing to you, simply ask, “Why is that important, Dr. ______?” Include the physician’s name so he or she knows you are being respectful but are simply confused by the questions.

If the physician starts to signal the appointment is over, and you have not had all of your questions answered, say, “Wait--I still have a few important questions here. The first one is...” And immediately ask the first one. Do not dawdle. Do not waste time looking for permission to proceed. Obviously, the physician is feeling pressure to move on to the next patient, so be respectful of that and ask your questions so you can both be done.

**IF THE PHYSICIAN STATES THAT HE/SHE IS OUT OF TIME, ASK:**

1. How can I best contact you to get the rest of my questions from this appointment answered?
2. How do I contact you in an emergency? To get a prescription refilled?
3. Do you correspond with patients by email?
4. Do you do phone appointments?
5. When do you recommend a follow-up appointment?
In summary, in order to be heard at your next appointment with a physician, do your work ahead of time. Prepare all the information discussed in this article, and print copies for the physician to keep, saving time for the staff. Know why you are going to this appointment, what you hope to accomplish specifically with this visit, and have your list of questions ready. Be respectful of the tremendous pressure your physician is under in terms of time and work duties, while keeping in mind that you have the right to have your medical needs met and your questions answered.

Make eye contact with your physician, be compassionate to your physician and understanding of the stressors affecting him/her, and always be an advocate for yourself! Follow up with your physician if you have any difficulty following any instructions given to you during your appointment. Be prepared. Be informed. And be strong!

References:


Question List for my Doctor Visit:

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________
From: ____________________________  
(Doctor/Practice Name)  

Re: _______________________________  
(Name of Patient)  

Please answer the following questions concerning your patient’s impairments. 
*Attach relevant treatment notes, radiologist reports, laboratory and test results as appropriate.*

1. Frequency and length of contact: _______________________________________________  

2. Diagnosis:  
- [ ] Mastocytosis (all variants/types)  
- [ ] Hereditary alpha Tryptasemia (HaT)  
- [ ] Mast Cell Activation Syndrome (MCAS)  

3. Which of the following symptoms are present in your patient:  
- [ ] Diarrhea  
- [ ] Lightheadedness  
- [ ] Weakness  
- [ ] Brain fog/neurocognitive dysfunction  
- [ ] Chest pain  
- [ ] Bone pain  
- [ ] Angioedema (swelling)  
- [ ] Throat swelling  
- [ ] Rapid heart rate (tachycardia)  
- [ ] Nausea and vomiting, abdominal pain  
- [ ] Syncope  
- [ ] Overwhelming exhaustion/fatigue  
- [ ] Itching, +/- rash, hives  
- [ ] Headaches  
- [ ] Anaphylaxis  
- [ ] Wheezing/shortness of breath  
- [ ] Low blood pressure/blood pressure instability  

4. If your patient has pain, characterize the nature, location, frequency, triggers, and severity of your patient’s pain:  
   ____________________________________________________________  
   ____________________________________________________________  

5. Identify the clinical findings and testing performed:  
   ____________________________________________________________  
   ____________________________________________________________  
   ____________________________________________________________  

6. Describe the treatment and response including any side effects of medication that may have implications for working (e.g., drowsiness, dizziness, nausea, etc):  
   ____________________________________________________________  
   ____________________________________________________________  
   ____________________________________________________________
7. As a result of your patient’s impairments, estimate your patient’s functional limitations if your patient were placed in a competitive work situation.

a. Will your patient sometimes need to take unscheduled breaks during a working day?  
   □ Yes  □ No

   If yes,
   1) How often do you think this will happen? ________________________________
   2) How long (on average) will your patient have to rest before returning to work? ________________________________
   3) What symptoms cause a need for breaks? ________________________________

b. How much is your patient likely to be “off task”? That is, what percentage of a typical workday would your patient’s symptoms likely be severe enough to interfere with attention and concentration needed to perform even simple work tasks?

   □ 0%  □ 5%  □ 10%  □ 15%  □ 20%  □ 25% or more

c. Are your patient’s impairments likely to produce “good days” and “bad days”?  
   □ Yes  □ No

   If yes, how often do you think this will happen?
   2) How long (on average) will your patient have to rest before returning to work?
   3) What symptoms cause a need for breaks?

   If yes, assuming your patient was trying to work full time, please estimate, on the average, how many days per month your patient is likely to be absent from work as a result of the impairments or treatment:

   □ Never  □ About three days per month
   □ About one day per month  □ About four days per month
   □ About two days per month  □ More than four days per month

8. Please describe any other limitations (such as psychological limitations, limited vision, difficulty hearing, need to avoid temperature extremes, wetness, humidity, noise, dust, fumes, gases or hazards, etc.) that would affect your patient’s ability to work at a regular job on a sustained basis:

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

Date ____________________________  Signature ____________________________

Printed Name ____________________________  Address ____________________________

__________________________________________________________________________

Address ____________________________
To whom it may concern:

______________________________, is a patient applying for disability for _________________________________.

Mast cell diseases, including mastocytosis and mast cell activation syndrome, are rare disorders as designated by the National Organization for Rare Disorders. Currently, there is no cure for mastocytosis or mast cell activation syndrome. Patients are maintained on a protocol of medications to control their symptoms and advised to adapt their lifestyle in such a way as to avoid known triggers, whenever possible.

______________________________, has a diagnosis of _________________________________, made by Dr. _________________________________ of _________________________________, in 20_____. Patients who receive appropriate care for mast cell diseases can have more positive outcomes, but they live a challenging life as they try to avoid triggers surrounding them and have to deal with the cascade of symptoms that result if they are exposed to such triggers. Mast cell diseases may arise as a clonal or non-clonal variant. Although these patients may not exhibit abnormal growth and subsequent proliferation of mast cells as seen in systemic mastocytosis, the function of their mast cells is impaired, resulting in many of the same life threatening symptoms, including the ever present risk of anaphylaxis in response to seemingly innocuous triggers such as heat, cold, temperature change, friction, vibration, anesthetic agents, perfumes and odors, insect and jellyfish stings and other venoms, certain foods, stress, medications, fatigue, infections, sun and exercise.

The symptomatology of these diseases is highly variable and unpredictable in nature, making it difficult for patients to know when they might suddenly suffer extremely disabling symptoms. The unpredictability of the onset of symptoms with no warning is what makes patients with mast cell diseases often unable to work at any job, inside or outside of the home.

Such symptoms may include: diarrhea with acute urgency, nausea and vomiting, lightheadedness which precedes syncope (fainting), weakness, overwhelming fatigue, brain fog and neurocognitive dysfunction, including difficulty with word retrieval, organizing thoughts, remembering tasks, uncontrollable itching with and without skin lesions, chest pain, migraine headaches, bone pain from osteopenia/osteoporosis and anaphylaxis. Symptoms can occur on a daily basis. It is impossible to maintain reliable attendance at a workplace, or even work from home, as symptoms may cause patients to feel very ill and need to rush to the bathroom.

Despite the strong desire to work and continue to be productive and to be able to be self-supportive, many patients with mast cell diseases are unable to work in any job in any capacity and be any kind of a reliable employee.

It should be noted that the average time from the onset of symptoms until a confirmation of diagnosis for mast cell diseases is nine years! Once a patient finally gets such a diagnosis, they are entitled to appropriate treatment.

Finding a physician to competently treat a patient with mast cell diseases is difficult; patients often have to travel long distances to access care, and it involves both travel and hotel costs to do so.
1. Offer the copy of The Special Edition for Health Care Professionals and refer to the page on Pediatric Mast Cell Diseases.

2. Explain that mast cells in cutaneous lesions release mediators that result in systemic symptoms, sometimes severe, such as flushing, nausea, vomiting, diarrhea, headaches, itching, difficulty concentrating, dizziness, etc. (add your child’s symptoms here).

3. Explain clearly how your child manifests early signs of deterioration or anaphylaxis, especially if it is not a typical presentation:
   - Does your child develop hives or swelling around the face, mouth or eyes, or develop flushing or pallor?
   - Does your child get an itchy, red rash (other than hives)?
   - Does your child develop a cough, especially one that can be staccato in nature in younger children, or may mimic their asthma cough?
   - Does your child develop frequent sneezing and/or a runny nose?
   - Does your child exhibit shortness of breath?
   - Does your child complain of chest pain even in the absence of shortness of breath?
   - Does your child complain of a mouth or tongue that feels funny? (Note: this may happen well before any visible oral swelling can be recognized or appreciated on exam.)
   - Does your child exhibit hoarseness or a change in voice?
   - Does your child clear his or her voice repetitively?
   - Does your child complain of trouble swallowing, or appear to be drooling excessively?
   - Does your child exhibit sudden abdominal pain?
   - Does your child develop nausea? vomiting? In some children, this may be the only initial symptom.
   - Does your child feel anxious, or tell you that something awful is happening?

   **You know your child best**, so be sure to educate the ER about how to recognize early anaphylaxis in your child.

4. Make sure that all medications and IV additives are alcohol free.
Thank you for your understanding of this patient who is totally disabled by ______________________, and who is unable to work because of their symptoms.

Date ______________________  Signature ______________________

Printed Name ______________________

Address ______________________

Address ______________________
Section II
Emergency Room Response Plan
Anaphylaxis in a Patient with Mast Cell Disease

*Please note: These recommendations may differ from general guidelines for anaphylaxis in that they may include additional considerations specific for the Mast Cell Disease patient.

PLACE PATIENT IN RECUMBENT POSITION AND ADMINISTER

(Please check all that apply)

☐ Epinephrine 0.3 mL of 1:1000 IM (auto injector preferred*). Repeat 3x at 5-minute intervals if blood pressure <90 systolic

☐ Oxygen by mask or nasal cannula

☐ If trigger is present, remove trigger from the reaction if possible

☐ Benadryl (Generic: diphenhydramine) 25–50 mg intravenously (slow IV push) every 2–4 hours, or cetirizine 10 mg intravenously, or Hydroxyzine Hydrochloride 25 mg intramuscular dose every 2–4 hours

☐ IV Fluids 1–2 L of Normal Saline until SBP is >90

☐ Albuterol by nebulization / Alternatively, Racemic Epinephrine can be given by nebulization

☐ Solu-Medrol (Generic: methylprednisolone) 0.5–1 mg/kg X1 and repeat 1–2 hours later if SBP below 90

☐ Glucagon** for patients on beta-blockers who do not respond to Epinephrine or who have cardiac disease that make continued boluses/treatment of Epinephrine contraindicated

☐ Optional: Prednisone 1mg/kg orally

Call 911 and take the patient to the closest emergency room. Please ask for a serum tryptase level to be drawn within 30 minutes of symptom onset.

A special ‘Thank you’ to Mariana Castells, MD, PhD, Director of the Boston Center of Excellence for Mastocytosis, Brigham and Womens’ Hospital, Boston, MA and Professor of Medicine, Harvard University; and Joseph Butterfield, MD, Director of the Mayo Clinic Program for Eosinophilic and Mast Cell Disorders, Mayo Clinic, and Professor of Medicine, Mayo Medical School, Rochester, MN for their contributions to the revision of the protocols.

*Auto injector avoids errors due to similar appearance of Epinephrine and other Ampules

**NOTE: the use of Glucagon is associated with a risk of nausea and vomiting. This can be due to the risk of increased cardiac oxygen demand, arrhythmias, coronary artery vasospasm. Recall that if the patient is on a non-selective beta blocker, administration of epinephrine will give a nearly pure alpha adrenergic effect, resulting in a spike in BP followed by triggering of carotid and aortic baroreceptors and a reflex increase of vagal tone resulting in bradycardia. Selective beta-1 blockers are less of a problem because the beta-2 receptors are not blocked and can offset the alpha receptor effect somewhat, lowering the risk of a spike in BP etc. (Joseph Butterfield, MD)
**Pre-Medication Plan**
For major and minor procedures/surgery and for radiology procedures, including ultrasound, with and without dyes.

**ADMINISTER**
At 12 hours and 1 hour prior to surgery or dye administration give:
(please select all that apply)
- **Benadryl** (Generic: diphenhydramine) 25 mg orally or IV, or **Atarax** (Generic: hydroxyzine) 25 mg orally, or equivalent non-sedating antihistamine. Examples: Zyrtec (cetirizine) 10 mg IV or PO may be used as a long-acting alternative, Claritin (loratidine), Allegra (fexofenadine)
- **Pepcid** (Generic: famotidine) 20 mg orally. Example: Tagamet (cimetidine)
- **Singulair** (montelukast) Examples: Accolate (zafirlukast), Zyflo CR (zileuton)

**Medications to Be Avoided**

**AVOID**
- Any medication to which the patient has a listed allergy
- Aspirin and nonsteroidal anti-inflammatory medicines if the patient has a known adverse reaction
- Morphine and codeine derivatives (fentanyl is the preferred opioid)
- Vancomycin given IV. Oral route may be tolerated in some patients.
- Quinolones

Please note this is a standardized protocol. Each protocol should be personalized for the patient with the help of a mast cell specialist. Some institutions/medical departments have their own protocols. **Be sure to discuss in advance with your physicians and those departments.**

**Additional Orders**

Physician Signature ____________________________ Date ________________

A special ‘Thank you’ to Mariana Castells, MD, PhD, Director of the Boston Center of Excellence for Mastocytosis, Brigham and Womens’ Hospital, Boston, MA and Professor of Medicine, Harvard University; and Joseph Butterfield, MD, Director of the Mayo Clinic Program for Eosinophilic and Mast Cell Disorders, Mayo Clinic, and Professor of Medicine, Mayo Medical School, Rochester, MN for their contributions to the revision of the protocols.
Anaphylaxis in a Pediatric Patient with Mast Cell Disease

*Please note: These recommendations may differ from general guidelines for anaphylaxis in that they may include additional considerations specific for the Mast Cell Disease patient.

PLACE PATIENT IN RECUMBENT POSITION AND ADMINISTER
(Please check all that apply)

☐ Epinephrine 0.15 mL of 1:1000 IM (Pediatric Auto injector preferred*). Repeat 3x at 5-minute intervals if blood pressure is <90 systolic

☐ Oxygen by mask or nasal cannula

☐ If trigger is present, remove trigger from the reaction if possible

☐ Benadryl (Generic: diphenhydramine) 12.5–25 mg intramuscular or intravenously (slow IV push) every 2–4 hours, or cetirizine: Children over 6 months of age 2.5 mg IV. Children ages 5–10: 5–10 mg IV depending on severity of symptoms. Children over 12 years of age: 10 mg IV push over 1–2 minutes

☐ IV Fluids 1–2 liters of Normal Saline for 1–2 hrs until Systolic BP is >90

☐ Albuterol by nebulization / Alternatively, Racemic Epinephrine may be used

☐ Solu-Medrol (Generic: methylprednisolone) 0.5–1 mg/kg X1 and repeat 1–2 hours later if SBP below 90

☐ Glucagon for patients on beta-blockers who do not respond to Epinephrine or who have cardiac disease that make continued boluses/treatment of Epinephrine contraindicated

☐ Optional: Prednisone 1mg/kg orally

Call 911 and take the patient to the closest emergency room.
Please ask for a serum tryptase level to be drawn within 30 minutes of symptom onset.

*Auto injector avoids errors due to similar appearance of Epinephrine and other Ampules
Pre-Medication Plan
For major and minor procedures/surgery and for radiology procedures, including ultrasound, with and without dyes.

**ADMINISTER**

At 12 hours and 1 hour prior to surgery or dye administration give:
(please select all that apply)

- **Benadryl** (Generic: diphenhydramine) 12.5–25 mg orally or IV, or **cetirizine** (Zyrtec) 2.5 mg for 6 months and over; 5 mg for ages 5–10; 10 mg for age 12 and over; or **loratadine** (Claritin) 2.5 mg for age 2–5; 5 mg for ages 6–11; 10 mg for ages 12 and over
- **Pepcid** (Generic: famotidine) 10 mg orally
- Consider **montelukast** 4 mg orally

**Medications to Be Avoided**

**AVOID**

- Any medication to which the patient has a listed allergy
- Aspirin and nonsteroidal anti-inflammatory medicines if the patient has a known adverse reaction
- Morphine and codeine derivatives (fentanyl is the preferred opioid)
- Vancomycin given IV. Oral route may be tolerated in some patients.
- Quinolones

Please note this is a standardized protocol. Each protocol should be personalized to the patient’s needs with the help of a mast cell specialist. Some institutions/medical departments have their own protocols. Be sure to discuss IN ADVANCE with your physicians and those departments.

Additional Orders

________________________

Physician Signature

________________________

Date

A special ‘Thank you’ to Mariana Castells, MD, PhD, Director of the Boston Center of Excellence for Mastocytosis, Brigham and Womens’ Hospital, Boston, MA and Professor of Medicine, Harvard University; and Joseph Butterfield, MD, Director of the Mayo Clinic Program for Eosinophilic and Mast Cell Disorders, Mayo Clinic, and Professor of Medicine, Mayo Medical School, Rochester, MN for their contributions to the revision of the protocols.
Please see note under tests about having your own physician sign this form for follow-up

1. Serum Tryptase—upon arrival in the ER and three hours later. If hospital lab is outfitted with the Immunocap system, serum tryptase results are obtained in 4 hours or less.
2. 24-hour or spot urines for:
   • n-methyl histamine
   • prostaglandin D2 (PGD2)
   • 11-beta prostaglandin F2 alpha
   • Leukotriene E4
3. Complete chemistry panel
4. CBC with differential

You MUST have your allergist or primary care provider sign the bottom of this form stating that he or she will be responsible for the follow-up on the 24-hour urine collections. Otherwise, the ER physicians will be reluctant to order them since they cannot be sure of follow-up care. Remember to contact your physician for follow-up after discharge.

I agree to provide follow-up care for my patient, ____________________________
and will obtain the results of the 24 hour or spot urine collections that were initiated in the emergency room setting to provide appropriate care based on the results.

Printed Name of Physician

Signature of Physician                          Date

Contact Address

Phone Number                          Fax Number
Medications to avoid or use with caution in patients with mast cell disease in emergency situations

**Please note:** Some of the Medications to Avoid may be given if absolutely necessary, if given with a prep to stabilize mast cells. Please refer to one of our mast cell experts for instructions.

<table>
<thead>
<tr>
<th>Medication Type</th>
<th>Avoid or Use With Caution</th>
<th>Medications That Are Typically Tolerated</th>
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<tr>
<td><strong>General Medications</strong></td>
<td>• alcohol&lt;br&gt;• amphotericin b&lt;br&gt;• dextran&lt;br&gt;• dextromethorphan&lt;br&gt;• polymyxin B&lt;br&gt;• quinine&lt;br&gt;• vancomycin IV&lt;br&gt;• alpha-adrenergic blockers&lt;br&gt;• beta-adrenergic blockers</td>
<td>• calcium channel blockers&lt;br&gt;• centrally acting alpha 2 adrenergic stimulants&lt;br&gt;• aldosterone antagonists</td>
</tr>
<tr>
<td><strong>Pain Medications</strong></td>
<td>• opioid narcotics (may be tolerated by some individuals)&lt;br&gt;• Toradol (ketorolac)&lt;br&gt;• Non-steroidal anti-inflammatory drugs (unless the patient is already taking a drug from this class)&lt;br&gt;• fentanyl [may require adjunct treatment with Zofran (ondansetron)]&lt;br&gt;• tramadol</td>
<td></td>
</tr>
<tr>
<td><strong>General Anesthetics</strong></td>
<td>• atracurium&lt;br&gt;• doxacurium&lt;br&gt;• rocuronium&lt;br&gt;• mivacurium</td>
<td>• pancuronium&lt;br&gt;• vecuronium</td>
</tr>
<tr>
<td><strong>Local Anesthetics</strong></td>
<td>• benzocaine&lt;br&gt;• chloroprocaine&lt;br&gt;• procaine&lt;br&gt;• tetracaine</td>
<td>• bupivacaine&lt;br&gt;• lidocaine&lt;br&gt;• mepivacaine&lt;br&gt;• prilocaine&lt;br&gt;• levobupivacaine&lt;br&gt;• ropivacaine</td>
</tr>
<tr>
<td><strong>Intraoperative Induction Medications</strong></td>
<td></td>
<td>• ketamine&lt;br&gt;• midazolam&lt;br&gt;• propofol</td>
</tr>
<tr>
<td><strong>Inhaled Anesthetics</strong></td>
<td></td>
<td>• sevoflurane</td>
</tr>
</tbody>
</table>

References:
Medic Alert Bracelet/Jewelry

When deciding what to put on your medical jewelry, the first word should always be: **Anaphylaxis**!

1. Systemic mastocytosis, systemic mast cell disease, mast cell activation syndrome or hereditary alpha tryptasemia.

2. If, and only if, you are on a beta blocker, add the following:
   a. After Epinephrine, give Glucagon.

3. Medication Allergies: if you have 1 allergy, then list it. If you have multiple, then state “drug allergies”.

4. Food Allergies: if you have 1 food allergy, then list it. If you have multiple, then state “multiple food allergies”.

5. Latex Allergy, if you have one.

6. Medication, food, and latex allergies can be combined.

7. Next, add other illnesses: diabetes, dysautonomia, EDS, angina, thyroiditis, etc.
References:

Notes: