

EMERGENCY ROOM PROTOCOLS

A handy reference guide to provide everything you need for emergency room visits as a patient with a Mast Cell Disorder.

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Emergency Room Protocol

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Personal Health History Form To Review with Primary Care Physician or Specialist

Name: _____ Date of Birth: _____

Home Address: _____

Height _____ Weight Range: _____ Medic Alert Jewelry Phone Number _____

Phone Numbers: Home: _____ Cell: _____ Work _____

Primary care physician name and address: _____

In case of emergency, please contact (name and phone number):

Current Diagnoses: _____

Allergies: _____

Medications: _____

Physician Signature: _____ Date: _____

Emergency Room Response Plan

Patient Name: _____ DOB: _____ DATE: _____

If the patient presents with flushing, rash, hives, swelling, abdominal pain, nausea, vomiting, shortness of breath, wheezing or hypotension, respond:

Administer

- Epinephrine 0.3 cc of 1/1000 and repeat 3x at 5-minute intervals if BP < 90 systolic (0.1 cc for children under 12)
- Benadryl (Generic: diphenhydramine) 25-50 mg (12.5-25 mg for children under 12) orally, intra-muscular or intravenously (slow IV push) every 2—4 hours or Atarax (Generic: hydroxyzine) 25 mg (12.5 mg for children age 2-12) orally every 2—4 hours
- Solu-Medrol (Generic: methylprednisolone) 120 mg (40 mg for children under 12) IV/IM
- Oxygen by mask or nasal cannula 100%
- Albuterol nebulization

Pre-medication for major and minor procedures and for radiology procedures with and without dyes:

- Prednisone 50 mg orally (20 mg for children under 12) 24 hours and 1—2 hours prior to surgery/procedure
- Benadryl (Generic: diphenhydramine) 25-50 mg orally (12.5 mg for children under 12) or Atarax (Generic: hydroxyzine) 25 mg orally, 1 hour prior to surgery/procedure
- Zantac (Generic: ranitidine) 150 mg orally (20 mg for children under 12) 1 hour prior to surgery/procedure
- Singulair (Generic: montelukast) 10 mg orally (5 mg for children under 12) 1 hour prior to surgery/procedure

Drugs to be avoided:

- Aspirin and non-steroidal anti-inflammatory medications
- Morphine, codeine derivatives
- Vancomycin

Recommend: Tylenol

Additional Orders:

Physician Signature _____ Date _____

The Mastocytosis Society thanks Dr. Mariana Castells for this emergency protocol.



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LABORATORY TESTS TO RUN ON PATIENTS IN THE ER WHO HAVE HAD A MAST CELL DEGRANULATION EVENT

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 urines for:
 - n-methyl histamine
 - prostaglandin D2(PGD2) and
 - 11-beta prostaglandin F2 alpha
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 urine collections that were initiated in the emergency room setting, and will provide appropriate care based on the results.

Printed Name of Physician

Signature of Physician

Date

Contact Address

Phone Number: _____ Fax Number: _____



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MEDICATION BY INDICATION ORGANIZER

MAJOR ILLNESSES

MEDICATION LIST:

INDICATION #1:				
Drug Name & Strength	Generic	Dosage	How Often	Reason for taking this medication
EXAMPLE ONLY Gastrocrom 100 mg ampules	<input checked="" type="checkbox"/> Y <input type="checkbox"/> N	200 mg -2 ampules	4x Dy 30 min before meals	Stabilize mast cells in GI tract; Brain fog
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			

INDICATION #2:				
Drug Name & Strength	Generic	Dosage	How Often	Reason for taking this medication
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
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	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			

MEDICATION BY INDICATION ORGANIZER

INDICATION #3:		MEDICATION LIST:		
Drug Name & Strength	Generic	Dosage	How Often	Reason for taking this medication
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			

INDICATION #4:		MEDICATION LIST:		
Drug Name & Strength	Generic	Dosage	How Often	Reason for taking this medication
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
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	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			

MEDICATION BY INDICATION ORGANIZER

INDICATION #5: <input type="text"/>		MEDICATION LIST:		
Drug Name & Strength	Generic	Dosage	How Often	Reason for taking this medication
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			

INDICATION #6: <input type="text"/>		MEDICATION LIST:		
Drug Name & Strength	Generic	Dosage	How Often	Reason for taking this medication
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			

OTHER ILLNESSES

INDICATION #7: <input type="text"/>		MEDICATION LIST:		
Drug Name & Strength	Generic	Dosage	How Often	Reason for taking this medication
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			

MEDICATION BY INDICATION ORGANIZER

INDICATION #8:		MEDICATION LIST:		
Drug Name & Strength	Generic	Dosage	How Often	Reason for taking this medication
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			

INDICATION #9:		MEDICATION LIST:		
Drug Name & Strength	Generic	Dosage	How Often	Reason for taking this medication
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			

INDICATION #10:		MEDICATION LIST:		
Drug Name & Strength	Generic	Dosage	How Often	Reason for taking this medication
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			

INDICATION #11:		MEDICATION LIST:		
Drug Name & Strength	Generic	Dosage	How Often	Reason for taking this medication
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			

INDICATION #12:		MEDICATION LIST:		
Drug Name & Strength	Generic	Dosage	How Often	Reason for taking this medication
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			
	<input type="checkbox"/> Y <input type="checkbox"/> N			



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DRUG ALLERGY FORM

Drug Brand Name	Drug Generic Name	Type of Reaction to Drug	How Long Ago Reaction Occurred



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PHYSICIANS LIST

PHYSICIAN'S SPECIALTY AREAS

PRIMARY CARE PROVIDER • INTERNIST • FAMILY PRACTITIONER • PEDIATRICIAN • ALLERGIST/IMMUNOLOGIST • CARDIOLOGIST
 DENTIST • DENTAL SPECIALIST • DERMATOLOGIST • EARS, NOSE, AND THROAT SPECIALIST • ENDOCRINOLOGIST • GASTROENTEROLOGIST
 HEMATOLOGIST/ONCOLOGIST • NEPHROLOGIST • NEUROLOGIST • NEUROSURGEON • OPHTHALMOLOGIST • ORTHOPEDIST • PSYCHIATRIST
 PSYCHOLOGIST • RHEUMATOLOGIST • SURGEON-GENERAL • SURGEON-PLASTIC • UROLOGIST • DIETICIAN • PHYSICAL THERAPIST
 OCCUPATIONAL THERAPIST • OTHER

Physician's Name	Physician's Specialty	Physician's Address	Physician's Phone	Physician's Fax	Physician's Email
EXAMPLE ONLY Dr. Smith	Family Practitioner	555 Physician's Lane New York City, New York 12345	555-123-4567	555-123-4568	Drsmith@doctor.com



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QUICK REFERENCE GUIDE: MEDICATIONS TO USE AND AVOID IN PATIENTS WITH MAST CELL DISEASE IN EMERGENCY SITUATIONS

Please note: Some of the Drugs 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.

Medication Type	<u>AVOID THESE DRUGS</u>	Drugs that are typically tolerated
General Drugs	Alcohol Amphotericin B Anticholinergic drugs Dextran Dextromethorphan Ethanol Polymyxin B Quinine Vancomycin IV Alpha-adrenergic blockers Beta-adrenergic blockers	
Pain Medications	Opioid narcotics (may be tolerated by some individuals) Toradol Non-steroidal anti-inflammatory drugs (unless the patient is already taking a drug from this class)	Fentanyl (may require adjunct treatment with Zofran) Tramadol
Muscle Relaxants	Atracurium Doxacurium D-tubocurarine Metocurine Mivacurium Succinylcholine	Pancuronium vecuronium
Local Anesthetics	Benzocaine Chloroprocaine Procaine Tetracaine	Bupivacaine Lidocaine Mepicacaine Prilocaine Levobupivacaine Ropivacaine
Intraoperative Induction Meds		Ketamine Midazolam Propofol
Inhaled Anesthetics		Sevoflurane

References:

1. DVDs from the TMS Annual Conferences, 2006, 2007, 2008, 2009, 2010, 2011, 2012, 2013
2. Mastocytosis: Perioperative Considerations. V.A. Goins. AORN Journal. December 1991: 54(6):1229-1238.
3. Mastocytosis: Current Concepts in Diagnosis and Treatment. L. Escibano, C. Akin, M. Castells, A. Orfao, DD.Metcalf, Annals of Hematology(2002); 81 677-690.
4. REMA protocol for mastocytosis



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For information about mastocytosis and mast cell related disorders, direct your Internet browser to The Mastocytosis Society, Inc. Website:

<http://www.tmsforacure.org>

To contact The Mastocytosis Society, Inc. Board of Directors, you can email:

tmsbod@tmsforacure.org

medicalinfo@tmsforacure.org

The Mastocytosis Society, Inc. also maintains a message only phone line that patients and health care professionals may call to leave a message. A Board of Directors member will reply within 48 hours. This line is not monitored 24 hours a day; so if you have an emergency please call 911, or contact your physician on call for advice.

Call 909-206-2786 or 909-20MASTO

WHAT TO SAY UPON ARRIVING IN THE EMERGENCY ROOM: BRIEF SCRIPTS

1. If your problem is a full blown mast cell attack/mast cell degranulation/fainting/anaphylaxis:

I am ___ years old with a known systemic mast cell disorder, and I am having anaphylaxis. (Say this even if you have not experienced anaphylaxis before as any mast cell degranulation attack can result in full blown anaphylaxis.)

2. If your problem is something else, (virus, fracture, auto accident, etc) and your mast cells are already flaring up:

I am _____ years old with _____ (i.e. an injury to my left knee). I have a systemic mast cell disorder, and I am at high risk of anaphylaxis. I need to be treated immediately to prevent that from happening.

3. If you have cutaneous disease but have systemic symptoms from the mast cell mediators released from your skin lesions:

I am ___ years old and I have cutaneous mastocytosis with systemic effects from the release of mediators in my skin lesions. I am at high risk for anaphylaxis and need to be treated immediately to prevent that.



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ADDITIONAL WAYS TO ADVOCATE FOR A CHILD IN THE EMERGENCY ROOM SETTING

1. Offer the copy of The Special Edition of The Mastocytosis Chronicles for Health Care Professionals, and refer to the page on Pediatric Mastocytosis.
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.

MEDIC ALERT AND OTHER MEDICAL JEWELRY

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

1. **Anaphylaxis!**
2. Systemic mastocytosis or systemic mast cell disorder or mast cell activation syndrome.
3. If, and only if, you are on a Beta blocker, add the following:
On Beta blockers-give glucagon with Epinephrine.
4. Drug Allergies: if you have 1 allergy, then list it. If you have multiple then state “drug allergies”.
5. Food Allergies: if you have 1 food allergy, then list it. If you have multiple then state “multiple food allergies”.
6. Latex Allergy
7. Drug, food and latex allergies can be combined.
8. Next add other illnesses: diabetes, angina, thyroiditis, etc.

References:

1. Anaphylaxis. Mayo Foundation for Medical Education and Research, 1998-2010, February 2009.
2. What You Should Know About Anaphylaxis. American Academy of Allergy, Asthma and Immunology. February 2009.
3. Akin C, editor. Mast Cells and Mastocytosis. Immunol Allergy Clin North Am. Philadelphia: Elsevier; 2006 Aug; 26(3):465-476, 487-504, 515-529, 541, 549-566.
4. Akin C, et al. Mast cell activation syndrome: proposed diagnostic criteria. J Allergy Clin Immunol. 2010 Dec;126(6):1099-104 e4.
5. Castells M, editor. Anaphylaxis and Hypersensitivity Reactions. New York: Humana Press; 2011.
6. Gotlib J. On being metachromatic: mystique and misunderstanding in mastocytosis. Am J Hematol. 2009 Dec;84(12):779-81.
7. Hamilton MJ, et al. Mast cell activation syndrome: a newly recognized disorder with systemic clinical manifestations. J Allergy Clin Immunol. 2011 Jul;128(1):147-52 e2.
8. Lieberman P, et al. The diagnosis and management of anaphylaxis practice parameter: 2010 update. J Allergy Clin Immunol. 2010 Sep;126(3):477-80 e1-42.
9. Norred CL. Anesthetic-induced anaphylaxis. J Am Assoc Nurse Anesth. 2012 Apr;80(2):129-40.
10. Simons FE, et al. World Allergy Organization anaphylaxis guidelines: summary. J Allergy Clin Immunol. 2011 Mar;127(3):587-93 e1-22.
11. Kounis NG, et al. Kounis syndrome: a new twist on an old disease. Future Cardiol. 2011 Nov;7(6):805-24.
12. Lanier, BQ. Anaphylaxis Update. ACEP Now. 2013 Mar; Retrieved from www.acepnow.com/article/anaphylaxis-update.
13. Simons FE, et al. World Allergy Organization Anaphylaxis Guidelines: 2013 update of the evidence base. Int Arch Allergy Immunol. 2013;162(3):193-204.
14. Hernandez-Trujillo V, Simons FE. Prospective evaluation of an anaphylaxis education mini-hand out: the AAAAI Anaphylaxis Wallet Card. J Allergy Clin Immunol Pract. 2013 Mar;1(2):181-5.