



# MAST CELL HOPE

NEWSLETTER

November 2019 Edition

Welcome to our second newsletter. Inside you will find information, stories and updates.



**What we work for every day.**

**Join Today**

**Donate**

**Run a Fundraiser**

**[mastcellhope.org](http://mastcellhope.org)**



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## **From the President**

I would like to welcome Katie Pagano to the Board of Directors. Katie is a teacher and a mom to a young son with mast cell disease and HATS. She has hit the ground running and is working on some fun and exciting plans for early 2020. Katie worked diligently and inside this newsletter you will find our new 504 and IEP guide for parents of chronically ill children. We hope that this will assist you in advocating for your children in the school setting. This will be posted to our education page in the near future as well.

Inside is also a Friend/Caregiver help tip section and how to tips for allergy awareness for Ambulances/ First Responders.

We have been working hard with international partners, researching grants and keeping up with our patient inspiration social media accounts on Instagram and Facebook (Mast Cell Hope, Inc.)

**December 3rd is Giving Tuesday.** Please support us with a donation and ask friends and family to as well. Every dollar counts!!!

We truly are here for the right reasons. We are transparent and open.

Together is the only way forward.

Warmest Regards,

Bonnie Sica, President



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## **Quotes by: Marily Huntley RN, BS, MA**

"Imagination is more important than knowledge. Knowledge is limited, imagination encircles the whole world." Albert Einstein

### **How to support a loved one with Mast Cell Disease**

1. Have an open mind and believe them when they tell you their struggles. If you hear anyone say that they are crazy or making it up, defend them.
2. Do some research on their disease so you can better understand them.
3. Reach out by phone and visits. Social isolation can be a big problem. Take them out to something other than a restaurant, where they are comfortable and safe from allergies. Ask them to pick a place to go that is safe for them.
4. Treat them the same. Share your problems and struggles too. Helping others is very therapeutic and everyone wants to be needed.
5. If they cancel plans, don't get angry. Be understanding and ask them to reschedule when they feel well.
6. Follow their rules and needs about foods, perfumes, smells, fabrics etc that they are allergic too. Yes, we can be allergic to anything!
7. Ask them how they could use some help.
8. Include them in your life. They will let you know their limits. Listen to these limits and don't judge or offer advice on how to "make them better".
9. Know that self care is important for patients but also pushing ourselves is too. Don't assume that if a patient was really that sick they would just lay in bed all day.
10. Give them a hug.
11. Don't give up on them.



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## **Fundraising for Hope**

We are all patients and understand the financial pressures that chronic disease patients face. You may want to donate to Mast Cell Hope's research and education initiatives but are unable to. Did you know that you could run a fun and easy fundraiser using your social media accounts? Interested in helping, Contact us at [mastcellhope@gmail.com](mailto:mastcellhope@gmail.com)

## **Membership:**

We want to thank all of our new members for joining us and for financially supporting our growth, outreach and projects. Members will receive our newsletters first, have voting rights at annual meetings and have a chance to participate in our research studies. Membership is \$25.00 per year.

JOIN TODAY at [mastcellhope.org/membership](http://mastcellhope.org/membership)

## **Grant applied to:**

The volunteer team has been hard at work applying for grants. We will share as much information as we can. Just know that we are pursuing all avenues of funding.

Global Genes: Our grant was accepted and now we move to the final selection process. This is a capacity building grant. We would like to thank Global Genes for this opportunity.



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## **Developing a 504 Plan for your Child**

How can I keep my child with medical requirements safe at school? This is a question many families have to ask when sending their child to school for the first time. Beginning this process can be very overwhelming. This planning document was created to help support you in this process. An important first step to take is understanding what a 504 plan entails and how it differs from an IEP. Understanding these distinctions, before entering into a 504 meeting at school, can help you feel confident, informed, and ready to advocate for your child. The accommodations following the links below are suggestions and examples of what can be provided.

### **Understand what a 504 Plan is and how it differs from an IEP, the ADA, and IDEA**

Clarifying the requirements of Section 504 of the Rehabilitation Act of 1973, as amended (Section 504) in the area of public elementary and secondary education

- <https://www2.ed.gov/about/offices/list/ocr/504faq.html>
- <https://www.parentcenterhub.org/section504/> (information provided in Spanish)

### 504, ADA, Not IDEA

- <http://schoolkidslawyer.com/2017/12/06/what-is-a-reasonable-accommodation/> (504 vs. ADA)
- 

### What is the difference between a 504 and an IEP?

- <https://www.washington.edu/accesscomputing/what-difference-between-iep-and-504-plan>
- <http://www.mastokids.org/504-and-iep>
- <https://kidshealth.org/en/parents/504-plans.html>
- <https://www.understood.org/en/school-learning/special-services/504-plan/understanding-504-plans> (helpful videos)

### Section 504, the ADA, and Public Schools

- <http://www.ldonline.org/article/6108/>
- <https://www.understood.org/en/school-learning/special-services/504-plan/understanding-504-plans>
- <https://www.parentcenterhub.org/section504/>



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### Going to School with Mastocytosis

- <http://mastocytosisawareness.blogspot.com/2012/09/going-to-school-with-mastocytosis.html>

### Accommodations Versus Modifications

- <http://acentral.education/learning-library/accommodations-vs-modifications>
- <https://www.understood.org/en/learning-attention-issues/treatments-approaches/educational-strategies/the-difference-between-accommodations-and-modifications>

**Symptoms may vary widely between individuals. Symptom severity will also vary. Your child will require a unique set of accommodations. The following list provides examples of what accommodations could be asked for.**

### Introduction of your child:

Write an introduction of your child. Let the school community get to know your child as an individual to allow for a connection to be made before the school year starts. Give an overview to which Mast Cell disorders your child has and any comorbidities. Provide info graphs and visuals so the school can better understand your child's medical conditions. Explain how these diseases/disorders impact your child specifically. Briefly, provide your child's story, medical history, and specific triggers that he or she may struggle with. Pictures of previous reactions are helpful when asking the school community to know what to look for.

**\*\*Do not give a school permission to contact your child's physician unless it is a last resort and you should be on the phone call. School system employees may ask questions in such a way that the physicians response is not correct pertaining to your child. \*\***

### Example:

School: Dr. A, do all children with Mast Cell Disease need a 24/7 bathroom and nurse pass?

Response: No, not all children. Just those that have chronic diarrhea or anaphylaxis.

School: Great, this child has never had an accident and has always made it to the bathroom on time and we never used an epi pen on them.



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The issue is that the school comes into the conversation with preconceived notions and then may tell parents that they spoke to the physician and they don't need a 24/7 bathroom pass.

### **Accommodations that can be sometimes included in a 504:**

#### **1. Management of food and allergies in the classroom**

- **You can declare that food provided to your child can only come from home.** You may want to discuss cross contamination at drinking fountains, access to water, who specifically needs to be made aware of your child's allergies and who should be trained to use the EpiPen, who specifically should be made aware of the 504 plan and any other plans that may be in place, such as anaphylaxis plan and asthma plan, clearly defined boundaries from contacting doctors without written permission from parents.
- **Removal of the most severe/airborne/contact allergens from the classroom**  
A letter should come from the school but can be co-written with parents or written by the parents and provided to the school. Depending on how severe the allergy, maybe certain items can be banned from the classroom.
- **Lunch/snack and cross contamination**  
You can ask that children wash hands with soap and water or safe wipes before and after eating food, tables are to be washed with soap and water or safe wipes after eating, establishing a safe place to eat such as an allergen free table or with a teacher/monitor, the teacher/monitor should be someone who is familiar with the medical plan in place who can closely supervise meal times to ensure your child does not come in contact with another child's food. \*\* Add in specifics to also ensure your child is not excluded, isolated, or sent back to the classroom so another child can eat a known allergen.
- **Soaps/cleaners/lotions/perfume/medical supplies/sunscreen/bug spray**  
You can request that your child only use safe soaps, cleaners, and sunscreen. If your child is reactive to products containing alcohol, you can request that Medical supplies that contain high amounts of alcohol not be used. Think about face paint and fake tattoos that may be used for celebrations.
- **Art supplies, school work supplies, musical instruments**  
Individual supplies and materials to prevent cross contamination of food that may be on a child's hands or mouth. Art projects involving nuts, seeds, fruit, dyes can be avoided.
- **Holidays, birthdays, and rewards**



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These times do not always have to be food oriented, no foods should be brought in that are made from home, all foods should have a list of ingredients to be checked, try to keep a bin in the classroom of safe snacks and treats that can be restocked. Previous notification is helpful when planning to bake a safe alternative.

### 2. **Playground and temperature needs**

If your child experiences cold induced urticaria, heat induced urticaria or flushing, exercise induced hives or anaphylaxis; you can request that your child remain indoors based on specific temperature and weather conditions for the day. Your child should not feel this is punishment but instead an opportunity to do something else that they enjoy.

#### **Mast Cell Reactions Unrelated to food:**

- Heat, cold, exercise, dampness in the air, humidity
- Physical education, recess
- Cooling vest
- Access to safe water
- Access to Air Conditioning (if possible in the school) If the school does not have AC, then what are the best alternatives for cooling (cooling vests, cool packs, fans.
- Signs of reaction (flushing, hives, lip swelling, burning sensation
- A designated teacher who is familiar with your medical plan can be assigned to monitor at these times
- Provide a protocol for onset of symptoms and reaction (when you see this-provide this, if you see this-do that, if you see these two or three things at the same time then... administer EpiPen
- What to do about insect bites or stings
- Field trips and events (parent or teacher familiar with medical needs will attend, bring medical bag, the same rules that apply in the classroom need to apply out of the classroom and on field trips.

#### **Clothing/accommodations made for cutaneous mastocytosis**

- Friction flaring a mastocytoma/ Urticaria Pigmentosa
- Clothing/ dress code accommodations to minimize irritation
- Access to creams/medications during a flare
- Identifying signs and symptoms that indicate a reaction due to a flare





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- Being excused from a current activity if a flare is taking place or if the activity can cause friction

### **Bathroom accommodations**

- Frequent bathroom breaks
- A sign that can be discreetly made to the teacher to indicate a bathroom break is needed or a 24/7 bathroom pass
- A designated bathroom to use so safe soap or wipes can be left for the child to use

### **Accommodations for taking breaks from work**

### **Emotional aspects of chronic illness and allergy / Help establish an Inclusive Classroom**

- Provide books, illustrations, pictures that depict differences among children in a positive light.
- Help establish positive talks in the classroom around what it means to have an inclusive classroom and how we can embrace and encourage our environments that support all children with a wide variety of needs.

**Bullying:** Speak to the teacher and ask them to keep a special eye out for teasing and children trying to intimidate a child by bringing an allergen close to them. Some children are comfortable with a presentation by the parent and teacher about their illness. Telling fellow students that this disease is not contagious and going over good friend rules are both important. Allowing the student to ask questions can be a great help.

### **Emergency anaphylaxis plan and allergic reaction**

- What is the plan?
- Who will have it?
- When will the plan be carried and what medical supplies will accompany it?
- What would need to accompany the child if he or she would have to be brought to the ER?

### **Medical absences/ illness**



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- All absences due to medical illness should be excused with a note from a parent or doctor, depending on how many days your child was absent
- If a virus or illness is in the classroom, parents can be contacted as soon as possible, and the classroom can be cleaned thoroughly before your child returns

### **Medications**

- What medications does your child take?
- How do they need to be kept?
- How do they need to be administered?
- If a reaction occurs, what medication should be administered?
- If child is old enough and can verbalize need for administration of additional medication, a letter will be provided from parents and doctor to give permission to provide such additional medication upon child's request, if these specific symptoms occur
- Medication storage and accessibility
- Emergency plan posted

### **Teacher Training in identifying symptoms of a reaction and anaphylaxis, how to administer an EpiPen, when to administer an EpiPen, where medical pack will be stored,**

- Teachers have to be trained in administering an EpiPen, but some districts allow for an online tutorial that is not very comprehensive. You can request that teachers and staff that have contact with your child go through a more thorough, in person training.
- If you are comfortable and well trained yourself, you may ask to personally speak to the staff in how and when to administer epinephrine specific to your child.
- You may also request to meet with school staff prior to the school year starting. In this meeting you can present your child, present resources and medical/emergency plans, as well as train them on signs and symptoms to look for in anaphylaxis and how to administer epinephrine.



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**Here is a downloadable and fillable guide from FARE for the Food Allergy and Emergency Plan. Every child should have this. We have added pictures of these forms on the next page.**

<https://www.foodallergy.org/life-with-food-allergies/food-allergy-anaphylaxis-emergency-care-plan>

We at Mast Cell Hope wish the best for your family and child. Always consult your physician about any information found in this document. Not all information will work for each child. We wanted to give you a jumping off point for you, your child's teacher, administrators and your child's physicians.

**This document will be available to the public on our education page in December.**



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**FARE**  
Food Allergy Research & Education

# FOOD ALLERGY & ANAPHYLAXIS EMERGENCY CARE PLAN

Name: \_\_\_\_\_

D.O.B.: \_\_\_\_\_

PLACE  
PICTURE  
HERE

Allergy to: \_\_\_\_\_

Weight: \_\_\_\_\_ lbs. Asthma:  Yes (higher risk for a severe reaction)  No

**NOTE: Do not depend on antihistamines or inhalers (bronchodilators) to treat a severe reaction. USE EPINEPHRINE.**

**Extremely reactive to the following allergens:**

**THEREFORE:**

If checked, give epinephrine immediately if the allergen was LIKELY eaten, for ANY symptoms.

If checked, give epinephrine immediately if the allergen was DEFINITELY eaten, even if no symptoms are apparent.

## FOR ANY OF THE FOLLOWING: SEVERE SYMPTOMS



### LUNG

Shortness of breath, wheezing, repetitive cough



### HEART

Pale or bluish skin, faintness, weak pulse, dizziness



### THROAT

Tight or hoarse throat, trouble breathing or swallowing



### MOUTH

Significant swelling of the tongue or lips



### SKIN

Many hives over body, widespread redness



### GUT

Repetitive vomiting, severe diarrhea



### OTHER

Feeling something bad is about to happen, anxiety, confusion

OR A  
COMBINATION  
of symptoms  
from different  
body areas.

- 1. INJECT EPINEPHRINE IMMEDIATELY.**
- 2. Call 911.** Tell emergency dispatcher the person is having anaphylaxis and may need epinephrine when emergency responders arrive.
  - Consider giving additional medications following epinephrine:
    - » Antihistamine
    - » Inhaler (bronchodilator) if wheezing
  - Lay the person flat, raise legs and keep warm. If breathing is difficult or they are vomiting, let them sit up or lie on their side.
  - If symptoms do not improve, or symptoms return, more doses of epinephrine can be given about 5 minutes or more after the last dose.
  - Alert emergency contacts.
  - Transport patient to ER, even if symptoms resolve. Patient should remain in ER for at least 4 hours because symptoms may return.

## MILD SYMPTOMS



### NOSE

Itchy or runny nose, sneezing



### MOUTH

Itchy mouth



### SKIN

A few hives, mild itch



### GUT

Mild nausea or discomfort

**FOR MILD SYMPTOMS FROM MORE THAN ONE SYSTEM AREA, GIVE EPINEPHRINE.**

**FOR MILD SYMPTOMS FROM A SINGLE SYSTEM AREA, FOLLOW THE DIRECTIONS BELOW:**

1. Antihistamines may be given, if ordered by a healthcare provider.
2. Stay with the person; alert emergency contacts.
3. Watch closely for changes. If symptoms worsen, give epinephrine.

## MEDICATIONS/DOSES

Epinephrine Brand or Generic: \_\_\_\_\_

Epinephrine Dose:  0.15 mg IM  0.3 mg IM

Antihistamine Brand or Generic: \_\_\_\_\_

Antihistamine Dose: \_\_\_\_\_

Other (e.g., inhaled-bronchodilator if wheezing): \_\_\_\_\_

PATIENT OR PARENT/GUARDIAN AUTHORIZATION SIGNATURE \_\_\_\_\_

DATE \_\_\_\_\_

PHYSICIAN/CPA AUTHORIZATION SIGNATURE \_\_\_\_\_

DATE \_\_\_\_\_

FORM PROVIDED COURTESY OF FOOD ALLERGY RESEARCH & EDUCATION (FARE) (FOODALLERGY.ORG) 4/2017



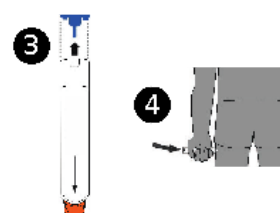
**HOW TO USE ALM-Q® (EPINEPHRINE INJECTION, USP), KALEO**

1. Remove Alm-Q from the outer case.
2. Pull off red safety guard.
3. Place black end of Alm-Q against the middle of the outer thigh.
4. Press firmly, and hold in place for 5 seconds.
5. Call 911 and get emergency medical help right away.



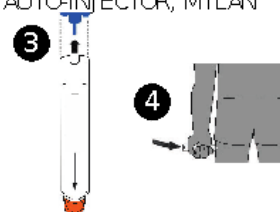
**HOW TO USE EPIPEN® AND EPIPEN JR® (EPINEPHRINE) AUTO-INJECTOR, MYLAN**

1. Remove the EpiPen® or EpiPen Jr® Auto-Injector from the clear carrier tube.
2. Grasp the auto-injector in your fist with the orange tip (needle end) pointing downward.
3. With your other hand, remove the blue safety release by pulling straight up.
4. Swing and push the auto-injector firmly into the middle of the outer thigh until it 'clicks'.
5. Hold firmly in place for 3 seconds (count slowly 1, 2, 3).
6. Remove and massage the injection area for 10 seconds.
7. Call 911 and get emergency medical help right away.



**HOW TO USE EPINEPHRINE INJECTION (AUTHORIZED GENERIC OF EPIPEN®), USP AUTO-INJECTOR, MYLAN**

1. Remove the epinephrine auto-injector from the clear carrier tube.
2. Grasp the auto-injector in your fist with the orange tip (needle end) pointing downward.
3. With your other hand, remove the blue safety release by pulling straight up.
4. Swing and push the auto-injector firmly into the middle of the outer thigh until it 'clicks'.
5. Hold firmly in place for 3 seconds (count slowly 1, 2, 3).
6. Remove and massage the injection area for 10 seconds.
7. Call 911 and get emergency medical help right away.



**HOW TO USE IMPAX EPINEPHRINE INJECTION (AUTHORIZED GENERIC OF ADRENALICK®), USP AUTO-INJECTOR, IMPAX LABORATORIES**

1. Remove epinephrine auto-injector from its protective carrying case.
2. Pull off both blue end caps; you will now see a red tip.
3. Grasp the auto-injector in your fist with the red tip pointing downward.
4. Put the red tip against the middle of the outer thigh at a 90-degree angle, perpendicular to the thigh.
5. Press down hard and hold firmly against the thigh for approximately 10 seconds.
6. Remove and massage the area for 10 seconds.
7. Call 911 and get emergency medical help right away.



**ADMINISTRATION AND SAFETY INFORMATION FOR ALL AUTO-INJECTORS:**

1. Do not put your thumb, fingers or hand over the tip of the auto-injector or inject into any body part other than mid-outer thigh. In case of accidental injection, go immediately to the nearest emergency room.
2. If administering to a young child, hold their leg firmly in place before and during injection to prevent injuries.
3. Epinephrine can be injected through clothing if needed.
4. Call 911 immediately after injection.

**OTHER DIRECTIONS/INFORMATION (may self-carry epinephrine, may self-administer epinephrine, etc.):**

Treat the person before calling emergency contacts. The first signs of a reaction can be mild, but symptoms can worsen quickly.

**EMERGENCY CONTACTS — CALL 911**

RESCUE SQUAD: \_\_\_\_\_  
 DOCTOR: \_\_\_\_\_ PHONE: \_\_\_\_\_  
 PARENT/GUARDIAN: \_\_\_\_\_ PHONE: \_\_\_\_\_

**OTHER EMERGENCY CONTACTS**

NAME/RELATIONSHIP: \_\_\_\_\_  
 PHONE: \_\_\_\_\_  
 NAME/RELATIONSHIP: \_\_\_\_\_  
 PHONE: \_\_\_\_\_



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## **Allergy and Anaphylaxis Awareness for First Responders**

It is very important to realize that a first responder may not realize that you are in anaphylaxis if you are unconscious. You could be in an accident and first responders need your information to treat you. Here are some ideas that you can do to protect yourself and get the right treatment as soon as possible?

1. Have a medical sheet typed up with your name, address, phone and date of birth. List your diagnosed diseases, current medications and known allergies. If you know your anesthesia protocol, list it as well. List all your physicians, their specialty and phone numbers. List your emergency contacts name and phone number. Keep this in your wallet and one copy in your glove compartment with your registration.
2. Get a medical alert bracelet or necklace. List your name, phone number, disease and if you have anaphylaxis.
3. Get a medical alert seat belt attachment. You can find these by searching on the internet. You can customize them as well.
4. If you call 911 and are conscious, remember to unlock your door, if they can't get in they will break it down. Turn a light on. Also, have your medical sheet hanging on your refrigerator or a place within easy access.
5. Spray paint your house number on the curb in front of your mailbox. Have your house or apartment number clearly visible near your door and on your mailbox.

**We wish everyone Happy and Healthy Holidays!**