



MAST CELL HOPE

NEWSLETTER

August 2019 Edition

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



We all spend days like this. Mast Cell Hope wants to change that.

Join Today

Donate

Run a Fundraiser

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Our logo:

The Mast Cell Hope logo was thoughtfully designed. **The shield** represents the immune system. The immune system protects us but with mast cell disease we also need protection from some of our immune cells. **Blue** represents Adults with mast cell diseases and **Purple** represents pediatrics. The **book** represents our education initiatives for medical personnel and the **beaker** represents our research initiatives. If you look at the **book and beaker together** it looks like an angel. There is hope in education and research.

Guidestar:

Mast Cell Hope has earned the Gold Seal of Transparency from Guidestar (now part of Candid). Guidestar is a leader in non profit company verification. Many donors go to Guidestar to review the charity that they are funding. Mast Cell Hope, Inc. is a 501C3 non profit and is available anytime a donor has a question at 860-621-9553.



Quotes by: Marily Huntley RN, BS, MA

" The universe is out there, waiting for you to discover it. "

Albert Einstein



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Disaster Preparedness: Information from the Red Cross Website

<https://www.redcross.org/get-help/how-to-prepare-for-emergencies/disaster-safety-for-people-with-disabilities.html>

What Do You Need In A Survival Kit?

At a minimum, you should have the basic supplies listed below:

Water: one gallon per person, per day (3-day supply for evacuation, 2-week supply for home)

Food: non-perishable, easy-to-prepare items (3-day supply for evacuation, 2-week supply for home).

Flashlight, Battery-powered or hand-crank radio (NOAA Weather Radio, if possible)

Extra batteries (Similar item available in the Red Cross Store)

Deluxe family first aid kit

Medications (7-day supply) and medical items

Multi-purpose tool, Emergency blanket

Sanitation and personal hygiene items

Copies of personal documents (medication list and pertinent medical information, proof of address, deed/lease to home, passports, birth certificates, insurance policies)

Cell phone with chargers (Similar item available in the Red Cross Store)

Family and emergency contact information

Extra cash

Map(s) of the area

Consider the needs of all family members and add supplies to your kit:

- Medical supplies (hearing aids with extra batteries, glasses, contact lenses, syringes, etc)
- Baby supplies (bottles, formula, baby food, diapers)
- Games and activities for children
- Pet supplies (collar, leash, ID, food, carrier, bowl)
- Two-way radios
- Extra set of car keys and house keys
- Manual can opener
- Work gloves, towels



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Additional supplies to keep at home or in your survival kit based on the types of disasters common to your area:

- Whistle
- N95 or surgical masks
- Matches
- Rain gear
- Tools/supplies for securing your home
- Extra clothing, hat and sturdy shoes
- Plastic sheeting
- Duct tape
- Scissors
- Household liquid bleach
- Entertainment items
- Blankets or sleeping bags

Be Red Cross Ready

Free Downloadable Disaster Plans from the Red Cross:

<https://www.redcross.org/get-help/how-to-prepare-for-emergencies/make-a-plan.html>

Mast Cell Hope 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



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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 letter of intent was accepted and now we can move forward to the full grant application process. This is a capacity building grant. We would like to thank Global Genes for this opportunity.

Grant Received: ANNOUNCEMENT !!!!

Google: We have worked very hard on a grant with Google over the last few months. We received the grant and we will receive in kind services of \$10,000 per month, a total of \$120,000 We are thankful to Google for all the free services that they have given our organization.

Donations

We need your help. If each person reading this donated \$50.00 we would be on our way to starting the Genome Research project. We can not get research done without funding. Our community needs this research. To donate you can go to our website at mastcellhope.org.

We know that money is tight for many of us. Would you consider running an easy fundraiser for your family and friends. You can do it right on facebook and it is a fun game. Their donation depends on their answers. Contact us at mastcellhope@gmail.com for more information.



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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

From the President

What a busy time it has been. So much good work being done. A huge thank you to our volunteers. Summer is a happy and joyful time. Filled with grilling, get togethers and fun. Also, unfortunately, hot weather that doesn't agree with my mast cells. Just a reminder that we are all patients, caregivers and friends.

It isn't easy starting a non profit. It isn't easy being the new kid on the block. Easy won't get us better testing, treatments or a cure. We need to realize that a lot of our fate is in our hands. We are a rare disease community and that means that we have access to less physicians, less research dollars and the stigma of having a disease you need to explain to everyone.

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

Together is the only way forward.

Warmest Regards,

Bonnie Sica, President