Are You Ready?

Emergency Preparedness Strategies & Resources

April 2, 2015
Emergency Preparedness:

A case for why it matters and what you should do.
Not Just Big ...

- Personal – medical emergency
- Institutional – Clinic or Center is closed
- Community – Power outage, transportation disrupted
- State/Regional – ice storm, hurricane, etc.
- National – loss of a critical medical food
Service is Collaborative

- When a part is down, can the service be delivered?
- When service is not available, there is an emergency!
It’s a Cycle

The effectiveness of the response depends on the level of preparedness.

The more you think about it, the quicker you will react, the less the damage will be, and the shorter the recovery.

It is often possible to mitigate the impact if you plan ahead.
Why should I care?

• You have to depend on yourself – others may also be impacted in an emergency.
• Your needs may be so special that resources may not be available for a while.
• Your network is only as strong as the weakest link – that may be you if someone else calls.
• Preparing is sometimes the best way to deal with the fear and anxiety of the unknown.

The first 72 hours are on you!
What should I do?

- Know your hazards and emergencies.
- Develop an emergency plan – include info from community and school plans.
- Assemble disaster supplies (go) kit.
- Learn how to shelter from all types of hazards.
- Know your community warning systems and evacuation routes.
- Learn what to do for specific hazards.
- Practice and maintain your plan.
Next Steps / Resources

- [https://www.fema.gov/media-library/assets/documents/7877](https://www.fema.gov/media-library/assets/documents/7877) - the “Are You Ready” guide
- [http://www.redcross.org/images/MEDIA_CustomProductCatalog/m12140360_ARC_Family_Disaster_Plan_Template_r083012.pdf](http://www.redcross.org/images/MEDIA_CustomProductCatalog/m12140360_ARC_Family_Disaster_Plan_Template_r083012.pdf) - Red Cross plan template
- [http://www.fema.gov/media-library-data/1390846764394-dc08e309debe561d866b05ac84daf1ee/checklist_2014.pdf](http://www.fema.gov/media-library-data/1390846764394-dc08e309debe561d866b05ac84daf1ee/checklist_2014.pdf) - FEMA’s Go Kit list
Contact Info:

- Bill Perry, EP Consultant to SERC: wrperry@eatel.net, 225-337-4234
- Dr. Hans Anderson, SERC EP Workgroup Lead: handers@tulane.edu, 504-988-5101
AUGUST 29, 2005
THE DAY THAT CHANGED EVERYTHING IN REGION 3
HURRICANE KATRINA MADE LANDFALL
SOUTHEASTERN REGIONAL GENETICS COLLABORATIVE (SERCC)

- REGION 3
- ALABAMA, FLORIDA, GEORGIA, LOUISIANA
- MISSISSIPPI, NORTH CAROLINA, SOUTH CAROLINA, PUERTO RICO, TENNESSEE, VIRGIN ISLANDS
- www.southeastgenetics.org
KATRINA DESTROYED THE INFRASTRUCTURE OF NEW ORLEANS

• Folks in our Tulane Hayward Genetics community who gathered at the Medical School to weather the storm had to be evacuated by Blackhawk helicopter.

• No power until October 30, 2005.

• Tulane Medical School opened some depts in December, but Genetics didn’t return until March 2006.
OUR SAFETY NET WAS GONE!

- No cell service
- No email availability
- State Pharmacy that distributed metabolic formulas statewide was under water
- No health units available for appointments, because they were evacuation centers
- No Newborn Screening lab—couldn’t test!
WILL WAS BORN!
October 17, 2005
“IGNORANCE IS BLISS”

- We had no idea what NBS was, much less how our lives were about to change
- Our genetics team had evacuated
- Dr. Andersson-Nantucket, MA
- Amy Cunningham, RD, LDN-Austin, TX
- Dr. Jess Thoene, Michigan
- Our genetics lab was under water
- Our son’s NBS was headed to ??
Day 11

- Routine NBS are drawn at 24 hours and results are returned by day 2-3-4.

- Children with some diseases rapidly decompensate if not being managed properly and can become critically ill.

- Will’s screening results were delayed to **Day 11**, so treatment started that day while we waited for results of confirmatory test.
NEW PARENT EMOTIONS

- FEAR
- ANXIETY
- HELPLESSNESS

These are likely the same emotions that our clinicians were feeling as they dealt with the evacuation. How would emergency preparedness help to make this easier?
WHAT HAVE WE LEARNED AS CONSUMERS?

**COMMUNICATION** is key

can patients and clinicians reach each other?

update contact info annually or more often

**REDUNDANCY** is imperative

we must have multiple ways to accomplish important tasks (lab/formula/medications)

**SELF ADVOCACY** strengthens the system

patients/parents/caregivers be prepared with extra supplies and an evacuation kit (different for each disorder)
Connectedness

- Social media has made it easier to stay connected
- LA has a yahoo messenger page and a facebook page by which we can stay in touch.
- Texting often works when cell calls fail
Stockpiles

- Not always possible due to prescription nature of our dry goods.

- Keep enough food/formula/medication at a family member’s house who lives out of danger zone.

- Speak to pharmacy and insurance company about providing these.
Any questions?
Emergency Preparedness
Resources for Families

www.GenesInLife.org/Emergency-Preparedness

What is GenesInLife.org?

• Genetics 101—How and why to get involved in research
• Comprehensive resource on genetic services
• Resources for before and after diagnosis

Help us connect individuals and families with quality information and resources around:

genetics, genetic services, and genetic conditions!
Tools for Organizing Information

www.GenesInLife.org/Emergency-Preparedness

Fillable Emergency Information Cards

• 53 conditions

Diagnosis: Maple Syrup Urine Disease (MSUD)

MSUD is an inherited disorder that prevents the body from metabolizing branched-chain amino acids (BCAAs) such as leucine, isoleucine and valine. Untreated MSUD causes ketonuria, irritability, poor feeding, encephalopathy, coma and respiratory failure.

If hospitalized, limit protein and provide high calorie BCAA-free formulas. Insulin and hemodialysis may be necessary.

American College of Medical Genetics (ACMG) ACT Sheets
http://www.acmg.net/resources/policies/ACT/condition-analyte-links.htm

In an emergency, call the Metabolic Specialist immediately.
Metabolic Specialist: ___________________________
Phone: ______________ Fax Discharge Summary: ____________
Primary Physician: ___________________________
Phone: ______________ Fax Discharge Summary: ____________
Patient Name: _______________________________
Address: _________________________________
City: __________________________ State: _____ Zip Code: ________
Phone: __________________________ Allergy(s): __________________

Sponsored by NYMAC (www.wadsworth.org/newborn/nymac)

Created by the New York Mid-Atlantic Consortium for Genetics and Newborn Screening Services (NYMAC)
Tools for Organizing Information

www.GenesInLife.org/Emergency-Preparedness

Portable Health Record Template

• How and why to create a PHR
  – Alerts & physician recommendations
  – Allergies
  – Procedures to be avoided
  – Physicians
  – Diagnoses
  – Medications, formulas, foods & supplements, etc.

Created by the Western States Genetics Services Collaborative
Tools for Organizing Information

www.GenesInLife.org/Emergency-Preparedness

Emergency Information Form for Children with Special Needs

• Created by the American Academy of Pediatrics & American College of Emergency Physicians

Sample Emergency Letter with Precautions and ER Recommendations

• Created by the United Mitochondrial Disease Foundation (UMDF)
Tips & Tools for Staying Connected

www.GenesInLife.org/Emergency-Preparedness

Emergency Preparedness for People with Disabilities
• Created by the Federal Emergency Management Agency (FEMA)
  -Creating a communications plan
  -Local and national agencies to contact
  -Building an emergency kit

Emergency Preparedness for Children with Special Needs
• Created by the Center for Children with Special Needs
  -Creating an emergency plan
  -Packing a supply kit
Resources & Services Specific to Your Region

www.GenesInLife.org/Emergency-Preparedness

www.nccrcg.org
Questions?

Contact Information

Bill Perry
wrperry@eatel.net

KC Singletary
ferrakc@gmail.com

Sharon Romelczyk
sromelczyk@geneticalliance.org

This webinar is an activity of the National Genetics Education and Consumer Network (NGECN). This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under Cooperative Agreement no. U22MC24100 (National Coordinating Center for the Regional Genetic Services Collaboratives, total award amount: $1,300,000). This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.