




NCC Collaborator

Expanding Genetic and NBS Services Through Multifaceted Partnerships



Preparing for a Newborn Screening Emergency? Just Ask Your RC

Providing seamless follow-up for the four million infants who receive newborn screening (NBS) tests and services in the United States each year is one of public health's greatest successes, especially when one considers the many steps and providers involved in the process. The NBS process involves birthing centers and hospitals; state public health laboratories and follow-up professionals; primary care providers and the medical home; genetic specialists; dietitians; metabolic food and pharmaceutical manufacturers; computer systems, databases and advanced communication modalities; overnight delivery services; not to mention families and their often medically-fragile infants.

Any glitch in the continuity of services in this complex system—from a local laboratory power outage to a disaster of the magnitude of Hurricane Katrina—may mean delayed treatment, and devastating consequences

on the lives of babies with positive newborn screening results, particularly those with metabolic disorders. For this reason, the HRSA Genetics Collaboratives (RCs) and their National Coordinating Center (NCC) have been addressing NBS emergency preparedness in a variety of ways since forming an Emergency Preparedness Workgroup in 2006. Workgroup meetings have brought together stakeholders from state and federal government agencies, industry, the healthcare community, and consumer groups to discuss shared concerns surrounding any disaster that might disrupt services, as well as to identify solutions. As readiness, response, and recovery ultimately occur in local programs, centers, and communities, each RC has been working toward solutions, featured in this issue of the *NCC Collaborator*, that address its unique needs. In some instances the RCs have worked together or partnered with other entities, and all have benefited from NCC's emergency preparedness consultant, William Perry, who provides his ten steps to preparedness on page 2 of this newsletter.

In the New England RC, planning has focused on the medical home, while the New York-Mid-Atlantic Consortium and

the Southeast RC have conducted tabletop drills that are being translated into real-time protocols. Similarly, the Western States RC is working with its member states to develop NBS emergency plans. In the Heartland RC, laboratory sample exchange drills, utilizing the Emergency Management Assistance Compact (EMAC), are demonstrating both the feasibility of sending samples to neighboring state labs and the ability to assure test quality. The Mountain States RC funded a project to identify resources to deal with the smaller, more frequent, localized emergencies they experience and it published a comprehensive report to guide stakeholders and serve as a stepping-stone to planning for major catastrophic situations. Finally, Region 4 has empowered families and caregivers of children with metabolic conditions with universal access to medical records and care plans through My-EIF, a web-based Emergency Information Form. Together, these efforts are building national preparedness systems that will benefit genetic centers, primary care, state public health programs, and families so that unforeseen circumstances will not disrupt newborn screening services and follow-up care.

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Emergency Preparedness P

Submitted by William Perry, Emergency Preparedness Consultant, NCC

At home, most of us have a few extra liters of water and some canned or dry food lying around, and some of us also have batteries and flashlights within reach. What about at work? Do you half-heartedly participate in your quarterly or twice yearly workplace evacuation drills? Perhaps you are the lucky clipboard-bearing employee who has been designated the accountability contact in those drills. Or perhaps, you've been away during the most recent rounds of emergency drills.

In the field of newborn screening and genetic services, it can feel overwhelming to think about your needs in an emergency. Where do you begin? It could be by putting together a list of patients and their contact information that you keep with you, establishing an emergency preparedness plan for your newborn screening lab, or finding out if you can incorporate your lab's needs into an existing preparedness plan. If you are a parent, is it by keeping a surplus of the costly medical foods your child needs on hand or by establishing multiple potential evacuation destinations? What if the emergency were to stretch on for weeks or months, or if more than one emergency occurs?

Whether you are a clinician, a laboratorian, a consumer, a parent, a dietitian, a genetic counselor, or a public health newborn screening program staff member, it is important to consider the four phases of emergency management: **preparedness, response, recovery, and mitigation**. A typical starting point is by conducting a needs assessment, developing plans

and then disseminating those plans and testing them through training and practice drills.

In addition, most newborn screening programs are part of a larger entity (academic department, public health department, etc.) with existing emergency preparedness plans, often as a result of regulatory mandate or best practice standards/certification expectations. In this situation, ask, "Do I fit into an existing emergency preparedness program?"

If YES, then take the following 10 easy steps to begin your participation in the process:

- 1** Identify who heads up your home organization's (academic department, public health lab, clinic, etc.) emergency preparedness efforts.
- 2** Discuss with this person where the preparedness program stands.
- 3** Obtain a copy of your home organization's emergency plans and procedures.
- 4** Review the plans and procedures and ask how the processes described impact your operations.
- 5** Compare what your home organization's plan identifies as likely or significant hazards with those hazards you think are most likely or significant for your department/program.
- 6** Define how your department would approach a situation where it could not provide services.
- 7** Establish a chain of command for emergencies, ensuring redundancy for senior-most levels. Formulate contact lists including alternate methods of contact based upon these command structures.
- 8** Identify at least one liaison to interact on your behalf with your larger home organization's emergency management structure during an emergency situation.
- 9** Determine the method and frequency of emergency plan review and formulate a list of the changes your program or center would like your home organization's emergency preparedness program to include. Ask your liaison to provide this feedback to your home organization's emergency preparedness meetings.
- 10** Take the materials developed in this process and formulate your plan and activation procedures to match your home organization's approach.

Planning in Ten Easy Steps

If your program and/or home organization does NOT have a formalized emergency plan or system in place, begin with the following easy steps:

1. Take a quick tour of the FEMA and NEMA business emergency preparedness websites to find information about developing an emergency preparedness plan:
 - <http://www.fema.gov/business/guide/index.shtm> (process defined)
 - <http://www.fema.gov/plan/prevent/howto/index.shtm> (mitigation actions)
 - <http://www.fema.gov/areyouready/> (for individuals)
2. Form a working group, comprised of one representative from each section of your department/program, to begin developing the emergency preparedness plan.
3. Create an emergency contact phone tree and alternative means of contact during an emergency (e.g., e-mail, hand radio, etc.).
4. Determine critical staff and reporting to work requirements and expectations during an emergency.
5. Begin to develop an emergency operations plan, field it to your workgroup, refine it, and then implement it in your office.
6. Develop a centralized list of suppliers/vendors and review how supplies are provided. Identify a person to help you ensure receipt of necessary supplies in an emergency.

“Whether you are a newborn screening public health program staff member, a clinician, or a consumer, you can begin emergency preparedness with fewer than 10 easy steps.”

7. Formulate agreements with the related suppliers.
8. Establish a method of contacting your patients/consumers should you be unable to provide services during the emergency (this can be done by keeping an emergency contact number for them in an excel sheet, a hardcopy list, an auto-recording with contact information, etc.)

If you are a consumer/patient, take the following steps to begin developing your plans in case of an emergency:

1. Identify multiple possible relocation sites (family, friends, etc.).
2. Develop an emergency *grab-and-go* kit containing:
 - a. An updated hardcopy print-out and electronic copy of your child’s medical record (you can scan hardcopies onto a USB flash drive that you add to, but also consider keeping an extra up-to-date electronic copy at the house of a relative or friend who does not live close by).
 - b. A list of medications (including dosage), in both hardcopy and electronic formats.
 - c. A list of insurance contact information in case you are out-of-state and out of their network.

- d. A list of supplier information for any medical foods, formulas, or supplements you might need.
3. Identify the genetic specialist/center (medical geneticist, dietitian, etc.) at each of your potential relocation sites and keep their information with you as part of the *grab-and-go* kit.
4. Talk with your usual medical providers about how to reach them in case of an emergency and understand how you fit into their emergency preparedness plans.

The above outlines the beginning of the work needed to prepare your organization and yourself to be ready in the rare event of an emergency. Once you have taken these steps, you will be poised to take the next steps and begin testing your plans and procedures. By reading this article, you have taken a critical first step: actively thinking about how to proceed in an emergency or disaster.

the new england **negc** genetics collaborative

Submitted by Chris Stille, MD, MPH, University of Massachusetts Medical School; Carl Cooley, MD, Center for Medical Home Improvement, Concord, NH and Medical Home Work Group Chair; Susan Waisbren, PhD, Children's Hospital Boston and Transition Work Group Chair; Karen Smith, Project Coordinator and Monica McClain, PhD, Project Manager, NEGC

Medical Home and Transition Work Groups Collaborate on the Development of a Care Planning Tool

At its inaugural meeting, the Medical Home work group of the New England Genetics Collaborative (NEGC) decided to develop and pilot a dynamic care plan instrument to be used as a communication tool among specialists, families, and the primary care medical home. In June 2009, Dr. Chris Stille, a medical home content expert, and the work group finalized plans to pilot a care plan communication tool that Dr. Stille had developed. The NEGC Innovative Project program provided additional funding for this project from June 2009 through May 2010.

The project consisted of further developing and refining the communication tool to be used with parents/primary doctors/specialists and testing it for feasibility in diverse pediatric practices, both as formal research and as a quality improvement activity. The goal was to create a practical care plan, a protocol for training physicians on its use, and a protocol for a brief coaching session for parents.

The care plan itself is a one-page form in an e-fillable PDF format (brevity is essential in busy offices). Based on the thinking that parents must be included in decision-making and communication, the form requires the



- *Parents made the form and coaching session more "family-friendly."*

The evaluation phase of the pilot began in Spring 2010. Unfortunately, the tool has not yet seen enough use to adequately describe its value. This is due, in part, to the low numbers of new eligible referrals and to doctors forgetting to use the tool. Further efforts are underway, using a quality improvement methodology, to overcome these and other obstacles to the tool's broad implementation. The first two steps in this process may be integrating the care plan into an electronic

parent and doctor to note what has been done and what plans and decisions should be communicated to other providers.

Focus groups with physicians and parents found that:

- *Parents and physicians (especially parents) felt strongly that the care plan would improve care and communication, and would help parents greatly in the shared decision-making process.*
- *Physicians were concerned about the time required to fill-in the tool. Ideally, the tool would be made into an electronic template that could be integrated into electronic medical records.*
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medical record to avoid duplication of work for the physicians, and ensuring that practices have a care coordinator or other "coach" available for brief education about how to use the plan.

<http://www.negenetics.org/>

Submitted by Katharine B. Harris, MBA, Program Manager, NYMAC

NYMAC Emergency Planners Move from Tabletop Drill to the Point of Care

NYMAC held an Emergency Preparedness (EP) Conference in Baltimore, Maryland on August 6, 2010. Thirty people, representing consumer groups, newborn screening labs and follow-up, programs for children with special healthcare needs, and specialty care centers attended the meeting. Morning presentations by Dr. Hans Andersson, a metabolic geneticist from the Southeast Genetics Collaborative (SERC), and Dr. Stan Berberich, a newborn screening scientist from the Heartland RC, focused on lessons learned from Hurricane Katrina and subsequent implementation of newborn screening specimen sharing, clinical emergency plans, and telecommunication exercises.

In the afternoon, a tabletop exercise moderated by the National Coordinating Center's EP consultant, William Perry, focused on the planning that would be needed in the face of an oncoming hurricane. The exercise resonated with many of the Mid-Atlantic participants, who have experienced blizzards and ice storms that paralyze transportation and knock out power for days at a time. Participants eagerly discussed their experiences and fears as they developed plans for what they would do in their assigned roles, both during the exercise and in their professional and personal lives afterward. Everyone agreed that more time was



needed to discuss responses, but all left Baltimore resolved to address emergency planning before the next crisis hits.

On November 1, 2010 NYMAC's Emergency Preparedness (EP) Interest Group held its first conference call. More than a dozen relived the August experience during this call and discussed what they have done and still need to do to be thoroughly prepared. Websites were shared including Family Voices' *Emergencies and Disasters: Keeping Children and Youth with Special Healthcare Needs Safe* (http://www.fvnd.org/yahoo_site_admin/assets/docs/DisastersEmergencies.274112605.pdf), *New Jersey's Special Needs Registry for Disasters* (<http://www.ready.nj.gov/media/pr071408.html>), and FEMA's multi-language Get a Kit/Make a Plan/Be Informed website (<http://www.ready.gov/>). Staff in the region's treatment centers are collecting emergency contact information from patients and families and ensuring that families have access to treatment plans for their child's condition and a way to contact

their providers with questions about treatment 24/7. Newborn screening program staff is talking with colleagues in other states about sending and receiving specimens and lab results. Several

people have participated in emergency drills at their own hospitals or public health sites.

Future activities for the NYMAC EP Interest Group include implementing a newborn specimen exchange modeled on the Heartland RC's program; publicizing the NYMAC Emergency Information Cards that are available on our website for each condition in the newborn screening panel (http://www.wadsworth.org/newborn/nymac/emergency_cards.html); identifying special needs shelters and registries and publicizing them through the NYMAC mailing list and in the quarterly NYMAC newsletter and sharing and implementing Mr. Perry's *How Do I Get Started: Recommendations on How to Initiate an Emergency Preparedness Program in the Newborn Screening Setting*.

<http://www.wadsworth.org/newborn/nymac>



SOUTHEAST NBS & GENETICS COLLABORATIVE

Submitted by Hans C. Andersson, MD, FACMG, Project Co-Director; William Perry NCC Emergency Preparedness Consultant and Phaidra Floyd-Browning, RN, Project Coordinator (Tulane), SERC

Results of a Catastrophe: How a Real Emergency Led to Emergency Preparedness in SERC

In August 2005, Hurricane Katrina caused levee breaks and widespread flooding in New Orleans. This resulted in the deaths of over 1000 residents and left tens of thousands stranded without food and water. As the first major US city to evacuate its inhabitants, New Orleans was closed for six weeks and left without utilities for many more. In the aftermath of this catastrophe, it was difficult to re-establish healthcare services; the main public hospital, Charity Hospital, has never reopened.

Despite all of this, medical genetic services were re-established within two weeks by taking advantage of previously established statewide clinics in facilities in outer New Orleans that were not closed. The Louisiana newborn screening labs, which were destroyed in the flooding, arranged to have the Iowa State Hygienic Lab perform all newborn screening tests under the Emergency Management Assistance Act (EMAC) within 10 days; newborn screening would not be re-established within Louisiana for two years. The only clinical biochemical genetics lab in Louisiana was closed for four months, but metabolic patients were able to have their lab tests run at other institutions (University of Maryland, Children's National Medi-

cal Center and University of Miami Miller Medical School).

These favorable outcomes for the vulnerable medical genetics patients in Louisiana during this period occurred in spite of a lack of emergency preparedness (EP). Since Hurricanes Katrina and Rita, the Southeast Regional Collaborative (SERC) has not only created emergency preparedness programs for its clinical teams, laboratories, and consumers, but has led the way for the other Regional Collaboratives (RCs) in EP. This article reviews the major EP efforts undertaken within SERC.

In August 2006, the first of several EP conferences was held in New Orleans to identify initial steps and develop plans for regional EP. Attendees included newborn screening genetics program directors, clinical genetic team members (physicians, nutritionists, counselors), laboratorians, and consumers. The meeting began with a bus tour of various affected neighborhoods of New Orleans. During the next day, breakout groups met to discuss issues related to regional access to care, coordination of laboratories, and command and control. The groups resolved to develop a plan that would reflect several key principles essential to EP and address:

- Establishment of command and control hierarchy;
- Enduring methods of communication within an impaired infrastructure; and

- Development of regular and ongoing exercises and activities to demonstrate EP competency.

Discussions of centralized versus decentralized command and control occurred without reaching a clear consensus.

SERC has created an ongoing EP Workgroup that meets bimonthly to discuss projects related to EP and to plan EP exercises. In May 2008, the workgroup unveiled a strategic plan for all members of the Southeast region to consider. The plan was made available on the RC website (<http://www.southeastgenetics.org>) and was e-mailed to members of the Collaborative. The plan described the circumstances during an emergency related to continuity of care for genetics professionals and patients and suggested first steps each genetic center, laboratory and consumer could take to initiate emergency preparedness. The plan was made more widely available through articles in the *NCC Collaborator* and the *ACMG Medical Geneticist*.

Genetic centers within the Southeast region have used the strategic plan to organize EP workshops for their staffs and patients. For example, the Greenwood Genetic Center organized a 1-day workshop in 2008, which brought together representatives from all five of its campuses throughout South Carolina to develop an emergency preparedness plan. This meeting led to widespread adoption of EP practices among over 100 center members and an ongoing process of EP that was tested during a subsequent ice storm in 2009. Representatives from



the SERC EP Workgroup, through NCC support have run/are planning regional workshops in NYMAC and the Heartland, New England and Mountain States RCs.

Additionally, emergency preparedness exercises have become a regular agenda item at the annual meetings of SERC and the Southeastern Regional Genetics Group (SERGG). In 2008, the SERC EP and Laboratory Performance Workgroups conducted a tabletop exercise to evaluate opportunities for interstate laboratory backup. One project that developed from the exercise was a survey to describe current practices of reporting newborn screening results. The results of the survey may lead to recommendations about improving reporting methods so that families who evacuate to other states and regions in emergencies can still receive timely evaluation and care of their newborns with presumptively positive NBS screening results.

In the 2009 tabletop exercise at the SERC and SERGG annual meetings, two teams of genetics professionals (clinicians, laboratorians, NBS coordinators) and consumers worked through an imaginary scenario in which one fantasy state threatened by an oncoming hurricane made preparations according to expected landfall and developed collaborative solutions with a second fantasy state. Participants learned the steps necessary to prepare for a predicted disaster and began to obtain the set of skills needed to develop EP in their own workplaces and homes. During the 2010 annual meeting exercise, two teams of genetics professionals and consumers used a remote virtual medical record developed by Region 4 (EIF) to evaluate mock genetics patients who had evacuated one region and subsequently arrived at a temporary healthcare shelter and an emergency room in another region. The team members used the remote medical record to identify

“These favorable outcomes for the vulnerable medical genetics patients in Louisiana during this period occurred in spite of a lack of emergency preparedness.”

the patients’ current medical status and develop a short-term medical care plan appropriate to their illness. This exercise demonstrated how access to remote healthcare records could facilitate the delivery of seamless care to patients with an established diagnosis and a care plan developed at another facility far away.

Emergency preparedness is an activity that is ongoing and needs continuous demonstration of competence through exercises and plan refinement. Both SERC and SERGG have an enduring interest in ongoing emergency preparedness education among their constituencies. The SERC EP Workgroup plans to produce additional exercises at annual meetings to develop new and refined skill sets. Because all interested parties cannot attend such exercises, the workgroup also plans to develop video modules that will help groups in the region develop step-by-step plans for developing EP and the required skill sets. While many of the Regional Genetics Collaboratives have engaged in EP, a well-established process for sharing between regions could lead to development of a national EP for all RCs and genetic centers. Ultimately, the principles of EP should become a clinical competency within genetics residency programs and all healthcare residency-training programs.

<http://www.southeastgenetics.org>



Region 4 Genetics Collaborative

Submitted by Sarah Wedepohl, MSW, Parent Coordinator and Sally Hiner, BS, LSW, Coordinator, Region 4

MyEIF: Emergency Preparedness from Region 4

Preparing for an emergency is important for all parents, but especially for parents of children with special healthcare needs. Many parents have daily care plans or long-term care plans for their children, but, when it comes to emergency preparedness plans, there are multiple factors to consider. MyEIF, “the web-based Emergency Information Form” formerly known as MEMSCIS,¹ is an easy-to-use, proven, online tool, designed to communicate critical information in an emergency about a child’s healthcare needs. We spoke with one Region 4 mom who uses MyEIF about her experiences.

Your son is seven years old now and you have been using MyEIF since he was a toddler. What drew you to the plan initially? Many parents have a written emergency care plan, but the fear that their plan will be nowhere near the child when the emergency strikes is one that is real for us. Our son has MCAD and we live in a rural area of the country. Our specialist first offered us the chance to start using MyEIF when our son was two years old, and once we learned about it, we took the opportunity to create a plan for him.

How does MyEIF differ from other types of emergency care plans? MyEIF can go anywhere with us. I don’t have to carry papers. Everyone who provides care for my son has a business-sized card with the MyEIF access information. His school takes the card



on field trips, out for recess and on the school bus.

How is MyEIF updated when medications, physicians or other information changes? Our doctors and nurses update it at each appointment. I can make a change to the plan too, and, when I do, every doctor on my son’s plan is notified by e-mail about the update.

What about security? Do you have concerns about the form being web-based? No, I feel that the information is secure. The site is well protected, and I have the password to give out if only I want to. If I give permission, someone can “break the glass” - meaning they can go into my son’s emergency plan without a password. It could take us up to 45 minutes to get to our son if we are working and he is at school. I need his emergency medical procedures information accessed

“The last thing I need is [my child’s medical record] to be at home and my child on the way to the hospital!”

much sooner than that. If a parent does not want the “break the glass” feature, they can disable it. I’m not concerned with security behind the “break the glass” feature because I know the people accessing the information have to provide their information as well.

Do you have any final comments? MyEIF provides a great free service. I would recommend it to any family.

Free and web-based, MyEIF.org provides access from any web-capable computer to information needed in an emergency. Doctors, nurses and parents can provide updates and print copies. There are layers of security that provide reassurance that those without permission to do so are not accessing personal information.

¹ MEMSCIS: Midwest Emergency Medical Services for Children Information System

<http://region4genetics.org>



Heartland Genetics and Newborn Screening Collaborative

Submitted by Patrick Hopkins, Lab Manager, Missouri NBS Laboratory

The Heartland NBS Back-up Testing and Quality Assurance Project

Flooding, ice storms, earthquakes, and tornadoes are a part of life in the Heartland states and can wreak havoc on infrastructure. Other unexpected events such as fires, or the discovery of black mold that caused closure of the Kansas NBS laboratory for two weeks, can occur. At the core of the Heartland Regional Collaborative (RC)'s emergency preparedness efforts is its NBS Back-up Testing and Quality Assurance Project, begun in 2007 as a joint effort between Dr. Stan Berberich (Iowa's NBS Laboratory Manager) and Patrick Hopkins (Missouri's NBS Laboratory Manager).

The first phase of this project successfully established and validated back-up testing services between Iowa and Missouri through planning, harmonization, and functional drills involving all the real players and real NBS specimens. The second phase expanded this process to the entire Heartland region. By May 2010, both phases were successfully completed.

The drills utilized the Emergency Management Assistance Compact (EMAC), which has tremendous benefits.

- The EMAC process allows states to avoid the lengthy, arduous, and often-restrictive procedures involved with forming Memorandums of Understanding (MOU's) between their states.

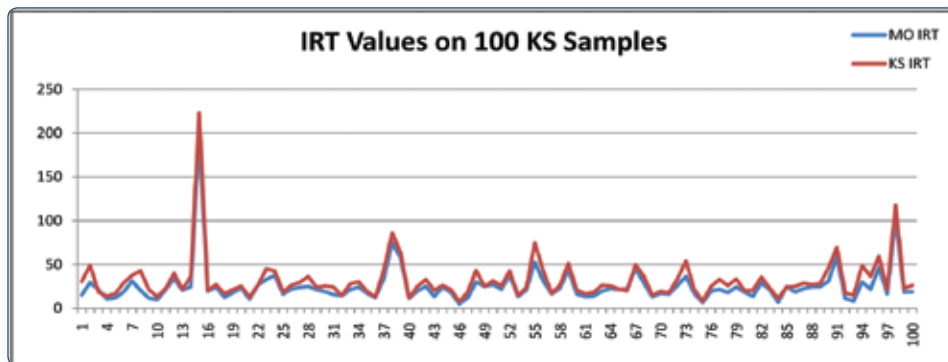


Figure 1: Ability to reproduce cystic fibrosis screening results on 100 samples shared between MO and KS.

- It is more versatile than other options, resulting in a better fit for each state's specific NBS needs.
- It can be utilized by any state in which the Governor has declared a state of emergency.
- The EMAC process is fast and simple, and the agreements can be amended during the recovery period to fit the circumstances.
- The 13 Articles of EMAC cover all the legal implications pertaining to state certifications, transporting specimens with patient information across state lines, and more. It also applies for emergency exercises! Furthermore, the drills helped the Heartland NBS labs establish and strengthen relationships with key personnel involved in local EMAC and between the labs.

Quality assurance was a significant additional benefit of these drills. Two-week-old samples that were completely reported out were exchanged between labs. This type of contrast testing of the NBS specimens could never have been done without the EMAC structure and provided an opportunity for the states participating in the exchange to learn from each other and improve

upon their current practices.

The parallel testing results of the drill samples were heartening. Not only were the labs able to detect the same true positive NBS cases, but the normal results were highly congruent. This further validates the fact that one state truly can successfully conduct testing for another. Figure 1 shows cystic fibrosis screening results on 100 samples shared between Missouri and Kansas.

With NBS back-up testing validated and implemented for the entire Heartland region, future plans include expanding the process to states outside the region. The Minnesota NBS program has successfully planned and carried out exchange drills with Iowa and Missouri, using a disaster state scenario and a supporting state scenario. The next step will be to build upon these efforts and conduct a drill with a high birth rate state whereby these three states would divide the sample load three ways to efficiently support the larger state's back-up testing needs.

<http://www.heartlandcollaborative.org/>



Submitted by Johan Van Hove, MD, PhD, Section Head, Clinical Genetics and Metabolism, University of Colorado at Denver and Advisory Council Member; Celia Kaye, MD, PhD, Project Director; Joyce Hooker, Project Manager and Liza Creel, MPH, Project Coordinator, MSGRCC

MSGRCC Project Explores Local Impact of Small, but Clinically Consequential, Emergencies

The impact of a major disaster, such as Hurricane Katrina, on the provision of genetic and metabolic healthcare delivery has received national attention.¹ In addition to rare major catastrophes, communities in the Mountain States Region and other areas of the country are vulnerable to critical clinical interruptions from small emergencies. Examples of these smaller, but more frequent, emergencies include:

- The prolonged unavailability of one or more clinicians or other key personnel (e.g., due to illness or accident), which can severely disrupt travel to outreach clinics throughout the region.
- Communications breakdowns, which can hinder the provision of care over a large geographic distance.
- Climatic events, such as a prolonged and severe blizzard, which can disrupt air and ground transportation and hinder the delivery of all services when they occur at the central node (e.g., Denver) or disrupt local services in more remote areas (e.g., Wyoming).
- A technical problem in a critical instrument in the biochemical laboratory, which can threaten the availability of emergency biochemical diagnostic services at the tertiary care provision center at a time when



hours count for the prognosis of a severely ill child.

Good stewardship of comprehensive genetic services requires providing continuity of care throughout small and large emergencies, and establishing preparedness plans in advance of an actual emergency. In 2008, MSGRCC funded a project to define smaller, but more frequent emergencies affecting genetic services in the Mountain States Region and to outline special considerations and available resources for preparedness planning activities targeting these potential emergencies. The report resulting from this project examines methods for assessing criticality of patient needs, identifying essential resources, assessing planning strategies based on the type and scale of the emergency, and maximizing the autonomy of the patient during an emergency. This analysis is based on services provided by the Clinical Genetics Services clinic in Denver, Colorado, which serves genetics patients in a large and diverse

geographic area. These services include the provision of clinical care, including the newborn screening follow-up, regional clinics throughout the states, and tertiary care at The Children's Hospital, Aurora, Colorado.

It remains important that local planning activities such as this take into consideration the recommendations developed nationally for major disaster preparedness. Conversely, we believe that preparedness for more frequent, but smaller emergencies will prove exceedingly helpful in developing plans for responding to larger catastrophes.

A copy of the complete report can be accessed at http://www.msgrcc.org/pdf_files/MSGRCC_Clinical_Preparedness_CO_WY_Final_Rpt.pdf.

¹Genetic/metabolic healthcare delivery during and after hurricanes Katrina and Rita. Andersson HC et al. *Mol. Genet. Metab.* 2006;88:3-6.

<http://www.msgrcc.org/>

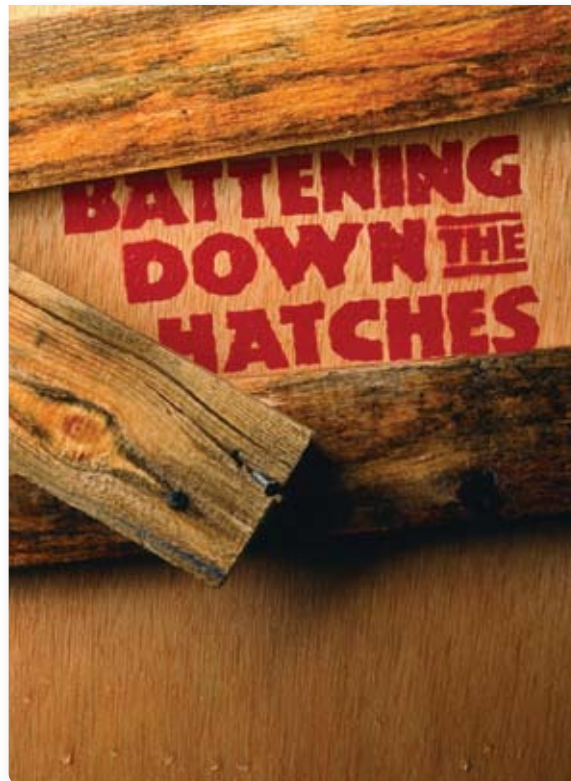


Submitted by Arthur Yu, MS, CGC, Project Specialist and Sylvia Au, MS, CGC, Project Director, WSGSC

In Case of Emergency: Emergency Preparedness in the Western States

Recent natural disasters, man-made accidents, and acts of terrorism have left many Americans deeply concerned about the impact future events could have on their lives. As a result, the issue of emergency preparedness (EP) has become a topic of considerable interest. Although the top priority of many EP plans is to ensure that individuals' and communities' basic needs are met, several Federal agencies (including HRSA and the CDC), HRSA's Regional Genetics Collaboratives (RCs), and their National Coordinating Center (NCC) have highlighted the need for EP plans that specifically address the challenges of providing timely follow-up for infants with a positive newborn screen, especially for an inherited metabolic condition, and continuity of clinical care for medically fragile children. To meet this need, each of the seven RCs has been involved in developing regional EP plans.

Currently, the Western States Genetic Services Collaborative (WSGSC) is working closely with our member states to address the issue. The WSGSC annual regional summit has been utilized as an effective forum to discuss EP related issues, beginning in 2009 when Bill Perry (NCC EP consultant) was invited to provide an overview of the NCC-endorsed points to consider for an EP plan for NBS. Building on this momentum, Arthur Yu gave a presentation at the 2010 regional summit summarizing how the Emergen-



cy Management Assistance Compact (EMAC) could be effectively utilized by NBS programs during a "state-of-emergency." The presentation is now being modified into an education module that will serve as a primer to introduce EMAC to a wide variety of audiences.

Two WSGSC member states (Alaska and California) have already developed state EP plans for NBS. Based on their experiences and input from the other member states, the WSGSC has decided to develop a more generalized EP plan rather than a detail-specific plan. This generalized plan could be broadly applied to many more situations, including both large and small-scale disasters.

Hawai'i has also started to address EP for NBS and held a meeting to introduce our NBS Program staff to the Hawai'i EMAC representative. The next step will be a follow-up meeting with the various NBS stakeholders to begin identifying the unique EP-related issues within our state. Given that the EMAC representative is an essential point of contact during an emergency, a contact list of each WSGSC member state EMAC representatives has been updated on the WSGSC website.

It is the hope within the WSGSC that a regional EP plan for NBS will allow the combined resources of the

member states to be made available during a "state-of-emergency" to provide interstate aid. The WSGSC has just begun the first steps towards this goal and is committed to ensuring that continuity of care for these medically fragile children is a priority.

<http://www.westernstatesgenetics.org>



NCC Calendar

NCC MEETINGS & NATIONAL CONFERENCES

NCC Medical Home Workgroup Meeting	Jan 26	Washington, DC
NCC Carrier Screening Task Force Meeting	Jan 26	Washington, DC
Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) Meeting	Jan 27-28	Washington, DC
Association of Maternal & Child Health Programs (AMCHP) Annual Conference	Feb 12-15	Washington, DC
Family Voices National Conference	Feb 13-15	Washington, DC
Society for Inherited Metabolic Disorders (SIMD) Annual Meeting	Feb 27 - Mar 2	Asilomar, CA
American College of Medical Genetics (ACMG) Annual Clinical Genetics Meeting	Mar 16-21	Vancouver, BC



NCC Collaborator

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