negc THE NEW ENGLAND GENETICS COLLABORATIVE

Emergency Preparedness Symposium Minutes

April 1, 2011

Welcome

The newborn screening (NBS) community has been thinking about emergency preparedness for some time. The goal for the day was not to be *ready*, but to think of ways to further the discussion.

Introductions

23 people attended.

- Most were from the NBS community (labs, NBS coordinators, clinicians) without expertise in emergency preparedness.
- Several were state or federal emergency preparedness contacts without expertise in NBS.
- Two were consumers with emergency preparedness expertise when it came to their families.

Presenters:

- **Stan Berberich**
  State Hygienic Laboratory, Iowa City, IA
- **Hans Andersson**
  Haywood Genetics Center, Tulane University, New Orleans, LA
- **Bill Perry**
  Emergency Preparedness Consultant, National Coordinating Center, Washington DC

Stan Berberich

Stan described his experiences when his NBS lab in Iowa supported Louisiana's lab after Hurricane Katrina. *The Heartland NBS Backup Testing Project* came out of that success (http://www.poststat.net/heartland/pub.1/issue.854/article.3435/).

The most important thing Stan learned is that it can be done.

There were issues translating data, just as all cars do the same thing but parts aren't interchangeable.

EMAC – Emergency Management Assistance Compact – became an important part of the event and helped get the legal people in the states to agree (http://www.emacweb.org/).

EMAC may be activated when a state's governor declares an emergency.

The Heartland region has begun running interstate drills. They are establishing that any one of the states can back up the other should there be an emergency.

Discussion after Stan's presentation included these points:

- *A governor has to declare emergency to put EMAC in place (doesn't have to be a disaster; could be "health emergency").*
- *If Maine uses a lab in another state and that lab has an emergency, the ME governor would still declare state of emergency.*
- *At the time of Katrina there was not an attempt to get parental consent to send specimens, and that approach has continued.*
- *There are many steps and a cost for governors to declare emergency, they don't do it easily.*
- *The important thing is planning; you can tell your governor that you aren't going to do anything without their declaring an emergency, but this is what you would do.*
- *Most people who have tried to get a written contract ahead of time haven't been successful.*

Hans Andersson

Hans shared his experiences during and after Katrina from his perspective as a geneticist caring for families in New Orleans.

No place in our country is immune from some kind of emergency.

All responses start locally. ***Most important thing is to know that you have to be and do for yourselves.***

Elements of emergency management plan:

- Procedures, structures, supplies, personnel
- Communications is important and not simple. Think of ways besides telephone and email.

Coordinate patient care before, during and after emergency.

When patient evacuates, receiving centers need information about their care.

Region 3, Southeast NBS and Genetics Collaborative (www.southeastgenetics.org), developed a regional disaster preparedness plan.

Barriers:

- hard to get people to spend time on something that may never happen to them
- Online medical records are not always available
- Obtaining Memorandums of Understanding (MOUs) for labs prior to an event is difficult.

Discussion after Hans' presentation included these points:

- *Doctors need to contact specialists re: handling cases that could deteriorate quickly.*
- *Families of those kids who decompensate do this planning every time they go on vacation.*
- *Consumers need to be educated; they could learn to have things on hand for a quick exit.*
- *For patients with metabolic conditions or others that could "go south" quickly, doctors should not only have an annual conversation about emergency preparedness, but should have a medical plan that says what to do.*
- *See December 2010 issue of* NCC Collaborator *for command control structures (http://www.negenetics.org/Libraries/National_transition_minutes/NCC_DEC_2010_Newsletter.sflb.ashx).*
- *People in emergency preparedness roles may not understand NBS but can help get things done.*
- *It is most important to be aware of your ESF8 (command structure used by FEMA) contact.*
    - *(ESF = Emergency Support Functions, 8 = designation for health and medical)*
- *Establish relationship first, do your planning, then in emergency you go to your contact and ask them to help you (go to the governor).*

Bill Perry

Bill introduced the Genetics Network tabletop exercise. He described two imaginary states, "Jefferson", and "Williamson", and set the scene:

> *"Hurricane Stan" is heading for Jefferson. Residents are told they will evacuate on Monday; today is Friday. Williamson will be helping them.*

All of the state/federal emergency prep people were asked to sit together to observe. The remaining attendees were divided into two groups (one for Jefferson, one for Williamson) consisting of these roles:

- Laboratory medical director/clinicians
- coordinator/follow up
- consumer

Participants imagined how they would respond given the scenario, including these highlights:

Jefferson Medical director:

- immediate things area related to communications, inventory, database in portable format
- as director he has lists of staff contact numbers
- talk to emergency prep contact about activating EMAC; could also ask about transportation, staff, tech support, moving materials

Jefferson Coordinator/follow up:

- make sure they have IT support for their database

- tell hospitals where future samples need to be sent; make sure hospital gets cell # of patients
- also wants to know how to contact specialists (cell #s)

Jefferson clinician:
- would prioritize patients

Jefferson consumer:
- Would want 1 page portable medical summary, all emergency numbers
- Use email and facebook (someone needs to create page) to contact other families
- Would need to pack, may have "daily packs" already made up
- Hopefully already made relationship with hotels. Hotels are part of the network.

Williamson Medical Director:
- how long do they think they will need his help, and is it feasible for his own staff to help
- do they have the same instruments; after testing is done, how will they interface
- would like list of all their facilities to enter into their own system;

Williamson Coordinator/follow up:
- contact ESF8 person and her counterpart in Jefferson
- assess capacity to help, including specialty clinics and diagnostic labs
- what communications systems are in place
- triage by severity; think about documentation requirements
- what are babies' physical locations; how do they get in touch; who are the specialists

Williamson clinicians:
- try to think of families that could serve as support people for similar families from Jefferson
- identify certain primary care doctors that would be good referral source for those families
- what other support do families need

Williamson consumer:
- would like timelines for contacting families, as well as for health professionals
- thinks most people would want to help

WHAT DID YOU LEARN?

- potential value of consumer to consumer interactions
- individual responsibility
- how much I don't know
- skip the MOU(and all the obstacles) and start work on planning
- it's all about expectations – need to have clear cut protocols
- need to have contact information
- importance of web site as a way to communicate

- need to think about the region as a whole
- resources on the web have to be up to date, easy to use, and people need to know about it

WHAT ACTION ITEM DID THE CONVERSATION PROMPT?

- continue the conversation; consider creating regional group to follow up
- work on planning and prioritizing
- establish clear cut protocols (who will contact whom)
- have two phone contacts
- talk about evacuation for serious cases in hospitals
- move toward electronic records/communication
- find out who I should be talking to back at my hospital
- develop more formalized agreements with help of NEGC
- would like web site like the southeast region
- develop checklist, not toolkit, for families of newly diagnosed children
- provide funding to family to family health centers to train and strengthen consumer networks

Suggestions from the emergency preparedness people:

- "Don't let the perfect be the enemy of the good." Even 50% planning is still better than nothing.
- think about storing information in a cloud, as data is so important
- find out who your ESF8 contact is and train them about NBS; you could also learn more about other ESF groups
- When you run drills, consider facilities (additional tradespeople, utilities, stock room, etc.)
- For chain of command, **Incident Command System (ICS)** – are the same in every state; learn more on their website: *http://www.fema.gov/emergency/nims/IncidentCommandSystem.shtm*
- *ESAR-VHP: Emergency System for Advanced Registration for Volunteer Health Professionals – way of credentialing people ahead of time so they can be deployed (doesn't include geneticists)*