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Increasing Awareness of Prenatal and Newborn Public Health Services in Preparation for Emergency and Disaster Situations

KATHARINE HARRIS: So, fast forward about nine months and the baby's here, we have a newborn screening. I want to thank everyone for being here and for the opportunity to talk about these projects that we're doing with the New York Midatlantic Consortium for Genetic and Newborn Screening and at the Wadsworth Center and with the National Coordinating Center. Just a little background on newborn screening, I know as, as MCH people, public health people, you all know a little bit about it, and but you can't start to talk about newborn screening without mentioning Doctor Robert Guthrie who is our father. Uh, he was in Buffalo and he developed the very inexpensive blood spot test, uh, about 1963. Before that he was testing diapers which, uh, we really didn't look forward to getting in the mail.

So New York state was not the first state, unfortunately, but we were pretty close to start screening for PKU, and we started in 1965, and since then we have screened over 11 million infants for PKU at, and all the other conditions that we added as, as time went by. We've identified 511 children, just in New York state,

who have PKU, and over, actually over 12 thousand infants have been identified in New York state with conditions on our, uh, panel.

Nationally, every state includes PKU, congenital hypothyroid, galactasemia and sickle cell disease. Most of the states are far more extensive than that, uh, and in fact, HRSA, the March of Dimes and the American College of Medical Genetics recommend a list of conditions, there's a, they're core conditions of about 29 conditions and I really hate conditions because we really are screening for chemicals, analytes, and those then lead to other, to specific conditions. But then there's a secondary, and this is where the secondary panel come up because since we're testing for analytes, there are more than one disease that may be abnormal depending on if an, if an analyte is, is wrong. So, depending on who's counting and how you count it, we're doing from 40 to 50 to whatever, uh, different conditions in many of the newborn screening panels, and our goal throughout the nation through these HRSA funded projects is to get the state's panels to be uniform.

Uh, just based on New York state data and, the number of infants born in the United States, probably at least 9,000 infants are diagnosed every year, should the full panel go, go into practice. And the point of newborn screening, as you know, is that delay in diagnosis, diagnosing most of these conditions until the clinical symptoms appear causes irreversible physical and or mental retardation or death.

So what happens when the lights go out or the water rises? Emergency preparedness, as you've heard, is to prepare procedures, agreements and to collect information which I think is almost more important than anything else, that will be needed in case of a newborn screening program shut-down. And once you've collected all that stuff, it's not gonna make a bit of difference unless you've tested it to see if it works, if it's flexible, if it's complete and if it's responsive.

So I've been working on a, sort of a several tiers. We started with the New York Midatlantic Consorti NYMAC, with a workgroup that's been looking at that. Then I, because I was asking questions the Wadsworth Center where, where New York state newborn screening takes place said, well, you can start doing that for Wadsworth Center for Newborn Screening. And we've been working all of the, all of the seven regions through the national coordinating center, and there's now emergency workgroup there.

The members of the NYMAC workgroup, we started out with our eight states and we invited, Massachusetts and Connecticut in the New England Region. We invited SERG, the Southeast Region, and they've sent people from Georgia and Louisiana. We invited people from the region formerly known as GLARG but they got Kentucky so they said they're no longer the Great Lakes Region. We've got representatives from there. And then we had a call from some people from the

heartlands. And we have a, somebody who works actually with a, manufacturing, uh, company out in California who's asked to work with us. We also do work with the CDC, the APHL, American Public, Health, Laboratories, Association of Public Health Laboratories, excuse me, March of Dimes. So have a lot of people involved in what we're doing.

What does it take to shut-down a newborn screening program? And you've seen, already seen Katrina, she's something that we all recognize at this point, and, who did that? Goodness. It blew away, very cool. and with Katrina the, the, the newborn screening in Louisiana was totally destroyed, apparently there was then a bidding war and within 24 hours they relocated all of their testing to Iowa.

Uh, floods, we had some major rains in June, last June, in New York state which washed out bridges. Didn't affect our newborn screening, but a lot of these, as I look over some of these problems, a lot of them disrupt, uh, delivery of our specimens, if nothing else, we can't get them.

Trenton, New Jersey and, this was part of the, the same, rain system that knocked out the, the, bridge in New York also closed down Trenton, New Jersey and this was especially problematic because this was the last couple of days of June and Governor Corzine in, uh, New Jersey was going to close the government because there was no budget. In New York, we're used to this, we just keep pretending we have a budget, it doesn't matter. But New Jersey takes it

seriously so, Allen Bergum who's the director of newborn screening in New Jersey was all set, they were gonna go in on the weekends and they were gonna get everything set and they had already identified all of their, players, and then the waters rose and they were closed out. And then, I couldn't find a picture of the newborn screening program being closed down, 'cause it was much more important that the casinos were closed, Doctor Bergum had apparently given his list of people who were essential to newborn screening, but they looked at the wrong list so he only had the supervisors and stuff so, uh, he didn't have data entry people, he didn't have all the lab techs that he needed, uh, it took a little while to get everybody approved to get them into the, the laboratory. He also had everything figured out except when they went to collect their specimens they realized that the New Jersey, since their lab was, their health department was basically closed down, their receiving, they weren't getting the mail, so they had to go over to the post office to get the mail, get the specimens that were coming in. So you talk about unforeseen consequences, and how were they gonna get the results in the mail? They had to walk them over to the post office.

Ice storms can, can shut-down, again, most of this is gonna be transportation issues, though an earthquake of this magnitude would probably close down the laboratory also. we had some grave concerns when, the planes hit the, Twin Towers, the World Trade Center, and we had several hospitals that were in this area that were birthing hospitals and we couldn't get their specimens through to Albany. our decision at that point was that we would test whatever came

through. We don't, we hope that all children were screened, we don't have any way to find out, but we tested whatever we got, no matter how old it was. When President Ford died, they closed the post office system so, how else are you gonna get your specimens? And this is, nobody knows what this is, it used to be when it was first put together it was 500 different cables and this is in 1993, electrician dropped a screwdriver into our transformer and blew out the whole of Wadsworth Center and the health department, and that's what the cable looked like after, after it melted. We were very fortunate, it happened on a late Friday, newborn screening, everybody else was off for about three weeks, but newborn screening was back in action with cables all over the floor and they were sitting out in the hallways where there happened to be ambient light because most of our labs are underground, but they were back in action by Monday. And the lights can go off, you might remember 2003, those of you who are in the Northeast, and the lights went off again. And then we are concerned about pandemic flu and that's gonna present a whole different set of issues from transportation or labs going down, that's going to effect our staff. Are the staff going to be able to get in? Are they going to be healthy enough to work? Are they gonna want to leave their families or are they gonna be afraid of that? Are we gonna make them stay? I mean, these are some interesting issues that, how are we gonna feed them? How are we gonna make, let them sleep if every, you know, if everybody's afraid and people are quarantined?

And of course at almost any time equipment goes down, Delaware has an ongoing agreement, uh, no, yeah, Delaware has an ongoing agreement with pediatrics when their mass spec goes down, we have in New York state we have five of them, so we do have some redundancy, but Delaware only has one or two and they can't, when there's goes down they have to send their specimens out.

So, the newborn screening program is just that, it's a program and it's a process. and interruptions in almost any part of this disrupts the whole thing, if you can't get communication, if you can't get specimens, if you can't get people, if you can't get reagents, and we were very acutely made aware of the consequences of newborn screening after Katrina, as Lori and Candace mentioned, when our patients who we've diagnosed and we feel a responsibility for, couldn't get their doctors, to their doctors, they couldn't get their supplements, they couldn't get their medications, they couldn't get their food. And since it was only one or two people, a lot of people weren't too worried about it, but, obviously the parents and the children were desperate to get their foods and medications.

So, most of these slides, and I'm gonna go through them pretty quickly, involve what you have to do before hand, and I maintain that you have to make lists, you have to make a lot of lists, you have to have contact information for all your birthing centers, you have to make sure that those centers have enough adequate supplies of blood collection forms, and they have to understand that even though these kids look well and even though collecting this heel stick

specimens are, might be a pain when everything else is going crazy, it's really important, and you have to have enough nursery staff trained to collect these spots. We get some very strange spots, we get blank spots even, that, that are insufficient for testing, we get coffee on our spots.

You got to look at different couriers. I mean if, if all of our stuff, New York state has just started, a couple, about a year ago, collecting all of our specimens. We have a contract with FedEx to go to every single birth hospital, every single day, and pick up whatever specimens. All of FedEx goes through Tennessee, we have this, uh, suddenly we have this nightmare, what if something happens in Nashville and all of our specimens are stuck someplace 'cause they can't get through? But there's also the, you know, so we, we need to make sure that at least whatever's still in the pipeline we can get.

for specimen testing, again you need all of your staff, you need information, what are their cell phones? What are their, home phones? You got, and you have to know what their responsibilities are, so you can triage, who, who's vital, who's desired? Obviously nobody's overstaffed, everybody's important, but it's really important to get everybody in. And then there's this question of a memoranda of understanding between states and among states to be a backup laboratory.

once you have the specimen and once you've tested it it's vital that you have lists of your reporting, who you're reporting to. I don't think you can have lists of

all of your reporting primary care docs, we don't even know most of them, I think, in New York State, half of them aren't real anyway. But you need to know all of your treatment centers and you need to make sure that they have an emergency plan that they have a list, an up-to-date list of their patients and how to contact those patients, that they have an up-to-date list of their pharmacies, of their providers. They need to know where they can send patients to get their special foods, their supplements and their medications. So we have to work closely with them so that, uh, they know where the patients are. In New York State, most of the, uh, most of the states in the Union do not have a really adequate long-term follow-up, we don't know where the babies are, but our providers have to know where they are and how to get in touch with them and how to communicate with them in case there's a problem.

All of our databases, we have extensive databases, I can ask our computer people, to go back 10 years and get me data on the patients who were diagnosed with this, that and the other thing. Those databases have to be backed up. New York state's is backed up, it's, actually it's mirrored so it's, there's an ongoing backup system, but it's just up the hill from us in another laboratory. Albany goes down, maybe Axelrod will stay up, maybe it won't. It's really vital that you have a database backup system that moves off sight. I maintain that it's really a fabulous idea that somebody or two or three sombodies in your program keep a stick that has all of the vital information, uh, you know, a memory stick or some binders. We're going to be putting binders of all of our

procedures and our protocols at our state emergency management, operations bunker so that if it goes down and we can't get into the laboratory, we have all of that stuff in case we have to recreate another laboratory, rather than go back to square one.

Talked about that, and again, you've got to communicate, and as, as, as Lori so beautifully described, if you can't communicate nobody knows that you're there. You need to get the word out that, A, newborn screening is really important even if everything else is going crazy, it's still very important for these few children who may be at risk. In fact, uh, I really love that the, I hadn't thought of putting, getting all of our faith based organizations, and that's where a lot of people go when there's an emergency. So it's one of the, you know, we've got government officials and we've got our staff and we've got our backup laboratories and our suppliers and our couriers, and our hospitals and our parents and the public programs, but we need the faith based organizations also. again, this is gonna be mostly the hospitals, our treatment centers are gonna have to keep these lists because we, New York State newborn screening, most of the state newborn screening programs don't know where all of their patients are. But they, somebody needs to know how to let these people know what's going on. We're talking about telephones, emails, public service announcements, school watch broadcasts, websites, and the emergency management sites.

Uh, how do you declare an emergency? You know, what part of the program's down, how long is it gonna stay down? What's the extent? Are neighboring states involved? We, New York state has some informal arrangements, and I'll mention that in a second, uh, with Massachusetts and New Jersey to, to serve as backups, but, it's just as easy that the whole Northeast could go out, so we need to know a little longer, uh, a little farther out, information on those newborn screening programs.

And, frankly, how important is newborn screening in the scope of, depending on the emergency? When Katrina hit all of New Orleans, public, you know, water was an incredibly important thing, housing was incredibly important, for a few children it, their, their conditions were the only thing that mattered but how do, you know, how do we, we get to triage and you got to be practical, resources are only gonna go so far.

when you talk about backup laboratories, you have to look at your numbers, and New York is a pretty big state, there are only four other states that are, have, more newborns. Are they going to be able to take our labs or are we gonna have to split them up? And the National Newborn Screening and Genetics Research Center is a really neat, uh, information database for its programs, for the newborn screening programs and what technology they're using, some of their cutoffs, some of their volumes.

Memoranda of agreements, some states can, can do that, I don't have a high regard for MOAs because I think it's impossible to get one through our legal, our, our state legal people because what if, what if, what if? Well, when it goes down, the what ifs are no longer, important. And if, so that's why we have informal agreements.

I'm, I'm after Katrina and with what happened, uh, with their newborn screenings going to, uh, Iowa, they invoked this emergency management assistance compact. Uh, I stated yesterday that every single state and Puerto Rico and the Virgin Islands have signed on to that. A number of people came up to me and said, I don't think we've signed up. Well, EMAC thinks they have, I've been on their website several times and they say every single state. In June they announced that Hawaii was the last one to sign up and everybody's done it. Uh, there may be some tepid signatures on there, or reconsidering. What that, two, two key issues that EMAC resolves are, liability and reimbursement, which are always an issue. Well, how are you gonna pay for that? Well, that's already been discussed and come to some sort of an agreement.

So your choices are, you know, neighboring states, can, can you divide the specimens? How are you gonna do that? some of the, in some of the newborn screening analytes are, you can't delay. If you don't find out that a baby's got PKU or Maple Syrup Urine Disease or Crab A Disease, New York is the only state in the Union to do Crab A Disease, but if you don't identify some of those

kids before they're symptomatic, you can figure it, especially Crab A, they need, those kids need a bone marrow transplant within about two weeks once they're identified as being at risk, otherwise it's useless, those kids are just gonna fade and die. Uh, PKU, if you don't get them on treatment within a couple of weeks they're gonna suffer irreversible mental retardation, and those kids are just gonna go into crisis and die.

Others have like cystic fibrosis or sickle cell disease, we've got time, those kids are probably gonna be okay for a few months. As we know with cystic fibrosis, those kids sort of run the gamut, if they're not identified by newborn screening they might spend, the average before newborn screening was 72 months to get a diagnosis and they were having, they would all be having respiratory and nutritional problems. But the data's still out in terms of how effective newborn screening is, we think it's a good idea to get those kids in treatment, but in an emergency we can wait a little bit of time.

Can you go back and get those blood cards? If they're in another state can you retrieve them once the issue's resolved and rescreen them, or, screen them for those analytes that you couldn't get to? And what about those kids who were missed, that never got screened at all? I think a lot of states are not able to identify to, to check their newborn screening specimens with their, with their vital records to find out who might have been missed?

Who owns a specimen? How will you pay for the work that a backup laboratory has, has, Incurred? And then how do you bring your databases up to, up to date? A lot of issues have to be discussed.

One more point, we're talking about central laboratory, uh the CDC is really excited about opening up a newborn screening laboratory that'll have everything, all, all different technologies, all different reagents, all different, conditions. If that's gonna happen, it's gonna happen way, way, way down the road, but, and then you'd have to cycle your staff and the newborn screening staff through to make sure they know how to use these, how, how, what's there at the CDC or at the backup laboratory, to make sure that they're proficient in, in where it is. Would they, and during an emergency, another question is, would they even go? You know, if your family, if you're worried about your family, would you move down to Atlanta for a few weeks to do newborn screening? That's, that's a concern. Iowa Hygienic Laboratory went 24-7 after Katrina, and they're looking very closely at, they're already there, they've already got the capability and the capacity, uh, of, I think, offering at least a limited backup laboratory capacity. And if you don't try, once you've got all your lists and all your arrangements made, if you don't test it you'll never have any idea whether or not it's gonna work, even then you can't come up with all of the different parameters that could go wrong. But if you don't, you've got to drill. And so I'm looking forward to getting some drill scenarios that we can use for newborn screening and see if any of our plans are going to work.

