

## **AMCHP 2007 ANNUAL CONFERENCE**

### **HEALTHY COMMUNITIES**

March 3rd to 7th, 2007

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

LORI WOLFE: Well, good morning. So, Candace had an opportunity to give you an overview of Teratogen Services and give you some information about what we do, our purposes and so on. And my role today is to talk to you about a specific project that we did with the CDC, this was actually with the National Centers on Birth Defects and Developmental Disabilities, that branch of the CDC. And this is, this did give us an opportunity to work with an emergency preparedness situation. So we're gonna talk to you a little bit about the background for our project, the fact that we actually did have this in the works for a couple years before we used it, before we needed it, what our methods, our goals, our results, and what we hope to do with this in the future and maybe some take home points that the rest of you can use.

So, originally what we did is we had started partnering with the CDC, Otis has worked with the CDC, um, quite a few times in the past few years, it's a natural partnership. And we came up with this quick response proposal that we had hoped to use in the case of potential emergencies. This was actually drafted by

Christina Chambers who was our past president of Otis in '04 to '06. She's an epidemiologist out with the California Teratogen Service. And what the idea was is that Otis is a very well established network, some of the teratogen services, for instance, in Utah you may be familiar with your service has been around for close to 30 years, the same in California. The services in Canada are very, very large and they've been around for many years also. So we already have this established network that we hoped could easily be streamlined into a situation where in an emergency that dealt with women who were pregnant and or breastfeeding, which most emergencies do, that we would be the go-to person that we would be known as the go-to organization that you would direct your pregnant women and breastfeeding women to call with any of their concerns. And again, we were working in collaboration with the CDC.

Now, in early 2005 when we were drafting this proposal, the things such as anthrax and the flu vaccine shortage, these were the kinds of things that we were thinking about, that we're getting as, um, going on this project.

So, what we hoped to do, again, was partner with the CDC, we wanted to, ahead of time, have some different responses, some different situations where we might be called upon, trying to plan for unanticipated events. We already do have an Otis toll-free number that works in both the United States, are providences and up in Canada. Some of you may be familiar with our 866 number, we have an area code routing system where, have any of you used our 866 number? You

call from your own state and if you're calling, for instance, within New York, you're gonna get routed to one of the New York teratogen services or in California or in Texas. If you are calling from a state such as Michigan, Minnesota, Florida, Oklahoma, that does not have a teratogen service, you're gonna get routed to your closest service, such as Oklahoma calls would come to me, or you're gonna get routed to the national, um, our national center, which is in Arizona, our national office.

So with every event, we would designate one service to be the first responder, usually having to do with their expertise in that area, or their location close to the emergency or the disaster, and then there would probably be a second site that would also be designated. We would publicize the toll-free number and the fact that we were the first responder or the first go-to person for this event for pregnant women, and we would be collecting data, again, in a protocol worked through with the CDC, where we could actually collect, record, and summarize our data for both the current and future projects.

Our target audience is generally pregnant women, as Candace mentioned we also hope to work always with women who are trying to become pregnant. Breastfeeding women are starting to make up nine to ten percent of the women who work with Otis, um, partners, family members, OBs, um, anybody who works with women. And, of course, in any emergency situation, we did realize that we

would want to contact the shelters and any type of temporary housing that would be involved in the national emergency, or local emergency.

Now, to publicize the project, these are the things that we were looking at to start with, and again, this was not in regards to any specific event, we were assuming that we would want to use newspaper, radio, TV ads, now, Otis doesn't have a lot of money so that's always gonna limit us in how much of these PSAs that we can do, online ads for websites, um, poster, flyers to whatever area's involved in the disaster, and of course, word of mouth by healthcare providers.

And all of our publicity would always stress that we are a free service. As Candace mentioned, most of our service is done over the phone, but we, all the services across the United States and Canada do encourage patients to actually come in to see us if you're within driving distance, in fact, in some of the smaller states, for instance, like Connecticut, they see most of their patients in person, Utah sees a great number, sees a number of their patients, so depending on where you are, you may see more patients in person. I have to tell you, in Texas we don't see, our state is so big and we also work with all of the surrounding states because there are not teratogen services in any of our surrounding states, so we do not see too many people in person, most of our, um, work is done over the phone or providing information, and/or providing information to their healthcare providers.

And then along came Hurricane Katrina, so this sort of immediately changed the direction of what we were doing with this. The CDC jumped in and said, this is a great opportunity for you all to be the first responders to an emergency of this magnitude. And as you're all aware about the pathway of Hurricane Katrina as it went over Florida and up through New Orleans. So now we decided to immediately implement this project that we had been working on. We started right after the hurricane in September of '05. We knew we would have some obstacles, because, again, we weren't really done with the plan, and we did not have a good network throughout the United States as far as who knows about us? Do health departments know about us? Do they immediately call Otis? Well, in some situations you do and in some you don't. We didn't yet have a model in place, um, and, of course, with dealing with something of the magnitude as the hurricane that went through New Orleans, as you're all aware, the communication systems no longer existed afterwards, so we found it very, very difficult to actually contact anyone to let the pregnant and breastfeeding women know that we were there. And as you might, um, assume, at the time that the hurricane immediately happened, we were not somebody that you would immediately be thinking about, because the initial issues of safety, you know, getting the family to a safe area, getting them out of the, uh, water or the bad situation that they were in, was of utmost importance. So we anticipated that the people who were using our service would be a few weeks to a number of weeks or even months after the initial event, when they had time, you know, they were in a safe, dry, warm place, they had some resources, and they had time to think

about, whoa, wait a minute, I was, you know, six weeks pregnant or I was six months pregnant, what, you know, might have happened to my pregnancy? Or, I was breastfeeding when I was there, what might have happened? Of course, manpower is always an issue too, with any project of this magnitude. And then along came Hurricane Rita, so we immediately incorporated that into our project, and the fact that we would take calls, obviously, from anybody who was affected by either of these hurricanes.

So, our first, um, obstacle, our first goal, was to make the public aware of the fact that we existed, to make toll-free phone counseling known to the people who were involved, to enable our system to handle these calls. And I have to tell you, honestly, we thought that there would be a lot of calls, so at the beginning we were really worried about, what's gonna happen? Some of us are very, as Candace mentioned, some of us are small teratogen services, often we only have two, three maybe four people working for the service, what's gonna happen if, all of a sudden, you have these floods of calls? Well in reality, that didn't happen. That was one of our learning experiences and that's something that we'll work to improve, but what we did was we modified the, um, 866 system so that it could handle calls, we added an option, so that if you call our 866 system, first you're directed to whether you need services in Spanish or English, and then your second button that you are directed to told you that if you had calls related to the recent hurricanes you should push button number two, which then would route you to, um, Arizona, which, again, is our national office, or to Texas. We

were chosen because of the fact that so many of the people who were displaced by the hurricane were actually coming to Texas. So we had a lot of people within Texas that needed our service. We had already established a database where we would record each call, we would record a number of features about the person who was calling, whether or not they were pregnant, how pregnant were they at the time of the exposure, were they breastfeeding, um, why were they calling? And we'll get into that more, what their actual concerns were, because we didn't actually anticipate all of the concerns that they would have during the hurricane and afterwards, and I think one thing we probably didn't anticipate is how many months afterwards it would take for these people to even get back home. You know, we had calls, six, seven, eight months after the hurricanes, where these people were just now returning to their homes in New Orleans and finding these homes, you know, in very, very poor conditions and they were very concerned about that.

So, who was involved? So we started off, of course, with Otis, this slide shows you the board of directors at the time that we did this project. Other key players, um, Hope Bergerman-Simpman was actually a master's level student, she, she was at that time working on getting her degree in genetic counseling, she heard about what we were doing and she decided to do her master's thesis on this Otis/CDC project. So that was very helpful and some of the data and the slides that I have are courtesy of Hope. And then we also worked with some of the

other people within Otis, with Jan Kragen and Sonia Rasmeusen within the CDC, with the American Red Cross, the March of Dimes and the EPA.

So what did we do, how did we start to publicize this? Um, we really tried a lot of different methods all at once, again, we were trying to get the word out there, by now it was the beginning of October by the time we got this in, this going, we were already four to five weeks past the hurricane, the initial hurricane. We went to WIC and Planned Parenthoods, we did a lot of flyer distribution, again, it was very hard to get the flyers into the, um, most severely affected areas. We went to a lot of faith based organizations, partly because they were housing the refugees, so a lot of the people who were displaced by the hurricane, I know even in Denton, you know we're in north Texas, just north of Dallas, and our church helped to house people, we had a lot of camps and churches within the area that helped to house people. A lot of people were bused to Texas.

Um, we also tried to do a lot public service announcements, radio, a little bit later I'll mention what we did with TV and newspaper. We did Otis website, CDC website, we got on the March of Dimes' website, um, we spent a lot of time trying to go to the state health departments within the affected states, but we found this was really hard, especially, again, if you were in an area that had been hit by the hurricane, you didn't necessarily have operating health departments, you didn't have, their offices were gone, their computers were down, we found it was very difficult to reach these people.

Um, again, the CDC, March of Dimes, there were some really helpful links, some helpful information that was put up pretty fast after the hurricane for women to go to and Otis was as a major heading on all of these websites, that if you were pregnant or nursing you should call Otis.

This is the flyer that we made, pregnancy and hurricanes, so this is the flyer that was sent out as much as we could widely distribute it. Again, we did it by hand, we did mailings, we did email distribution, anything that we could think of. We went to some of the meetings that were being held that fall, for instance, and SGC is the national Society of Genetic Counselors, we attended their meeting and told them, and that's a couple thousand people, about our project. Um, regional NAACP, so we tried anything we could think of to get the word out that we were there and we could help these people, it was free.

Um, as Candace mentioned, the Otis fact sheets were very, very important. We already had, at that point, about four to five dozen fact sheets, but we sat down and we brainstormed with the CDC what additional fact sheets should we be writing? You know, what can we get out in the next few months? Um, we partnering with the CDC and what we actually did was the fact sheets were written by Otis members, which could be physicians, genetic counselors, pharmacists, different people wrote the different fact sheets. Um, sometimes we have a lot of people who have masters in public health, things like that.

Um, we tried always to get the, uh, fact sheets written at an eighth grade level, we would edit and re-edit, and if you've ever worked, to some of you, I don't know if, are some of you CDC people? Um, it takes a long time if you're working with different branches of the CDC, so, what we finally ended up doing was, um, they were posted on the Otis website once they were approved by Otis, and then once they were approved by the CDC, they were posted on the CDC website also. And I have to tell you, some of those fact sheets have not made it yet, they're still going through the CDC, but they were posted on Otis as soon as we could get them up there, we tried by the end of '05.

So these are some of the ones that we came up with. Because, again, we were trying to think, if you're in a hurricane, flooding situation where you're getting a lot of negative environmental exposures afterwards, what are you concerned about? So, infectious agents we felt would be a big concern, um, Cytomegalovirus, hepatitis, influenza, um, some of these we already had, our toxoplasmosis, for instance, is a fact sheet we've had for many, many years. Some of these were written specifically after the hurricanes, um, stress and hypothermia, stress was one that was very, um, needed during this time, some of these medications that people were using and they were worried, um, other exposures, lead was a very big concern with all of the flood waters, of course, mold, everybody was concerned about mold, uh, pesticides, because, again, about, not only what was used at the time and afterwards, but a lot of factories, industrial areas were

flooded and the flooded waters, of course, went into the homes, so when the waters receded these people were very worried about this mud and sludge and the residues that were left in their house. That came back to the things like the solvents, the pesticides, the lead and so on. And of course, maternal depression, it's very, very depressing, obviously, to lose your home or to be in this type of situation, so we did receive a lot of calls about depression and the medications that you can use for depression.

Um, this just gives you an idea of the downloads, you have this handout, I know it's hard to read, but you can see 21 thousand, 23 thousand, almost 24 thousand. So we did have a lot of women, through the months of August into September after the hurricanes hit, and we recorded this all the way through April of '06, which was when our project with the CDC ended. So we actually were funded from September through April with the CDC, which is why we use this timeline. But it was interesting that the number of hits on the fact sheets that were related went up dramatically.

Again, as Candace mentioned, Otis as a group received 70 thousand to 100 thousand telephone calls annually, that includes Canada and I think Canada receives around 30 thousand of those, because they have a socialized, um, medicine system, their teratogen services are very well known in Canada and very heavily used.

So, we did make that change at the end of September to the routing system, we decided, again, that Arizona would be the primary, Texas would be secondary. So, what actually happened? Well unfortunately we didn't receive the hundreds of calls that we hoped we would receive. It was just so hard to get our name out there, to get this toll-free number out there, reality we only received 33 calls that were directly from people that had either been in the hurricane or come back home to their houses that had been destroyed by the flood waters and so on.

Um, again, we recorded calls from October 4<sup>th</sup> through April 27<sup>th</sup>, Arizona received 14 calls, these were through the 866 national number where people actually chose the hurricane, um, number two button. In Texas we received 19 calls, a few of these were from people in Texas using the national number, but in Texas we also have our own toll-free, um, teratogen number, 800-733-4727, and so a lot of these calls were from people within Texas who were calling us or people in New Orleans using our Texas number.

And I'm not gonna go through this in detail, but I wanted to point out a few things, I wanted to give you an idea when the calls came in, and you'll see, um, that in October we received quite a few calls, people were either just calling in general, we would get people who would say, you know, I was in the hurricane or I've come back home to my house, what do I need to be worried about? So sometimes they were just asking for general information. We had a lot of people concerned with the flood water, with drinking water quality. That was a common

concern, can I drink the water, again, when am I gonna be able to drink the water? Mold was a big concern because people were coming home to houses that were totally moldy.

Um, sometimes they got our number through their pharmacist or through their healthcare providers, often, again, through the websites that we had it listed. But what we decided, because we really weren't getting the calls that we needed to, we decided that we really needed to do outreach trips. And again, we underestimated how many months it would take for the repair system to start working, for people to start getting their telephone lines back, getting their computers back online, you know, for the, I know I went to a meeting her in D.C. in September and I met some of the people from the health department in New Orleans and they still weren't back in their offices, they were still in temporary warehouses, you know, miles from their offices, because their offices were still destroyed.

So we decided that even though it was now months after the hurricanes had hit that we really needed to go onsite, we needed to have some people down there handing out our flyers and talking to these people. So Doctor Luther Robinson, who's, um, our dysmorphologist from New York, he's actually up in Buffalo New York, and Hope, because she was working on this at this point, she was nearing her graduation, decided to do this trip to both Baton Rouge and New Orleans, and during a two day blitz visit as many people as they could. And this was very

helpful, they went to health departments, they went to some of the different WIC clinics, they really just blitzed and handed out as many flyers as they could. But unfortunately, again, so many people were still without offices, some of the WIC clinics, very few, at this point, you know, here you're talking months after the hurricane and yet only a few of the health departments and WIC clinics were back open, um, many people were out in high cost rental housings, so it was hard to actually find them and contact them. They did still realize the importance of the faith and the community and so they tried to go to all these different, um, shelters and community organizations. But it still really didn't have the impact that we were looking for. When I had an opportunity to visit Doctor Kevin Stevens who is the director of the city of New Orleans health department.

Doctor Stevens actually contacted us, he had heard about our program and he's like, hey, this is something I want to know more about, can one of you fly over here? And because I was in Texas and I'm on the board of directors I was like, sure, I'll fly over. So I flew over, I met with him, I gave him flyers to hand out at his city pregnancy clinics, the most important thing is he has a weekly television show, and he just loved our program, he said, you know, can I get on TV every week and I, can I tell the residents of New Orleans about you? And I said, sure. And in addition I met with Doctor Paula Zina who was at Tulane and I gave her flyers.

So after we met with them we had a big jump in calls, again. And most of the people either saw Doctor Stevens, they saw what he had to say, or one of his, uh, shows resulted in a newspaper article in the main New Orleans newspaper. So that, all of a sudden we saw this little jump in our calls. Most of these people were concerned about lead, they still had the sludge, they were still cleaning up their houses, they were worried about lead, they were worried about mold, and they were still worried about water quality.

So we sort of put this graph together, how did they hear about us? Well, in the end, five of them called because Doctor Steven's show, so that was a big percentage, or the newspaper article which was a direct result of his show. So, actually the biggest percentage overall of our few calls that we received came from me actually going and meeting, one on one with him, and he going on TV. So we knew how effective TV was, we just really didn't have a prior opportunity to use it. CDC was very helpful, the CDC website, the March of Dimes website, handing out our flyers to healthcare professionals made a big difference, we had a few calls from that.

Um, what were they worried about? You know, water, water was the biggest concern, whether it was the water that was still standing in their house, whether or not they could drink the water. Lead was a great concern, and this wasn't just pregnant individuals, um, I know I had some calls personally from moms of babies and toddlers because they had gone back home and they were trying to

clean up their houses and, you know, their toddlers were crawling around and getting this stuff in their mouth and they were worried that they were consuming too much lead. General information, air quality, solvents, bacteria, seafood, uh, DEET, so you've got some pesticides, and again, soil quality, smoke, I did get some calls right within a week after the hurricane happened, well, I'm sorry, they didn't call that soon but they were looking back at that time period, and they said there was a lot of heavy smoke hanging in the air, what was I exposed to?

So we did get calls like that, um, when we analyzed the project, the in-person publicity, the television, the newspaper worked best. Um, you know we didn't get the calls we anticipated, and this is something we're gonna have to work on. This project was really important as far as setting a groundwork, a lot more people in the various health departments knows about Otis know, the fact that we're on the CDC website, the March of Dimes website, we did a lot more community outreach, and I think that we are becoming better known. We did find out, which I'm sure you were aware of, that the United States did not have a good system so that in an emergency of this scope there was not anyway we could immediately reach a lot of people who were affected. We need to streamline our approach, we need to, you know, get down there, in person next time, much faster and actually be handing out the information and the handouts from shelter to shelter, from clinic to clinic, airport to airport. I know a lot of people were housed in situations such as airports. We need to have a good email tree system that we can immediately go to so that everybody, such as any of you for instance

who would be interested, would be on this list and right away you would know what's Otis doing? What handouts does Otis have? You know, where can I send my pregnant and breastfeeding women to Otis because of the exposure in question?

So again, this is just a thank you to the people who helped and the organizations that were involved.