

## **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**

CANDACE STEWART: Good morning, ladies and gentlemen. I'm going to be speaking to you guys today about just increasing teratogen awareness and basically about the services that our service as well as, our partners, uh, across the country provide. And then Lori will be following up with an example of how we were able to, kind of, implement our goals in, in an example of an emergency situation and then Katharine will be talking about her involvement in emergency preparedness.

And so, obviously, can I get a feel, how many people in here know, have heard of teratogen services before? Great. And then, obviously, everyone in here is aware of what a teratogen is, and so we know that anywhere from three to four percent of all babies are born with birth defects and 10% of those are caused by teratogens, which means that for every three to, or three to four out of every 1,000 babies that are born have a birth defect that is caused by teratogens.

And, as you guys indicated you are aware, but a teratogen is an exposure during pregnancy that results in an adverse pregnancy outcome, whether that be

miscarriage, stillbirth, low birth weight, infertility is also included in this. And then, as well, as breastfeeding, we address a lot of those issues as well, anything that you would be exposed to during breastfeeding that could harm the baby.

Common teratogens that you guys are, I'm sure, aware of, alcohol, smoking, diabetes, cocaine. So it can be maternal condition, maternal illness or maternal exposure. And we get a fair amount, of, of response to these teratogens but as well as many, many other things that people perceive to be potential teratogens at our teratogen information service, which I'll be talking more about in just a few minutes.

But I just think it's interesting that, this, this addresses the fact that exposures during pregnancy, are, are usually perceived to have a greater risk than is actual, and this leads to a lot of the anxiety and misunderstanding among the parents, , that we speak with, and, and hopefully that's a service that we provide is that we can, kind of, reduce some of that anxiety so that these, these women and families can enjoy their pregnancy a, a lot more, because they don't have to be so anxious.

I know that we get calls from, anywhere from someone who has a true teratogen exposure that they were taking Accutane while they were pregnant, or someone who, , I know I've had calls from women worried about drying their hair because of the, the heat from the blow-dryer, they're worried about swimming, they're

worried about, Lori has a great story of a mom who's, who's dad, she had a pregnant, she was pregnant with twins, big pregnant belly, and while she was sleeping he put dinosaur footprint stamps across her belly, and then she was terrified about the dye seeping into her skin and effecting her pregnancy. And obviously these are things that we understand to be a little, little worry, don't, don't increase their risk at all. But, but these women are, are terrified, especially if they've had adverse pregnancy outcomes in the past. They're, they're really cautious.

Now, we do know that teratogen, teratogen caused birth defects are preventable, so this three to four per thousand birth defects that are caused by teratogens are preventable because they're due to an exposure during the pregnancy.

So our goal, as teratology information services is to, kind of, bridge the gap between primary care providers and, and some of that anxiety that those parents, and families feel.

So, we kind of have a three, or three, three goals at Teratogen Services. We do, obviously, counseling, and services. We do pregnancy risk assessments, mostly over the phone, to our patients directly. And then we also are a resource for healthcare providers, whether they be doctors, nurses, WIC offices, abortion clinics, Planned Parenthood, those healthcare providers as well, use us as a resource. We do as much education as possible, whether they're lectures at high

schools with our college students, and we, we also do workshops with, with some of the healthcare providers whether they be, again be Planned Parenthood, WIC, as well as nurses. And, and our biggest push at a national level are these patient friendly fact sheets. We have about 65 available for download on our website. They are written, at an eighth grade level for, for public access and I'm going to talk about them a little bit more here in a few minutes. And we are involved in some research opportunities, and again, I'm going to address them in a later slide.

So this, kind of, how our calls break down. Again, as I said, most of our, our counseling is done over the phone. Teratogen Service is across the United States, we have anywhere from 13 to 16, depending on how the funding falls, they are open. And then we have three, uh, up to three in Canada. So there are about 70 thousand calls annually, and the vast, vast majority of those calls are either from patients themselves or from healthcare providers. We try to keep it about 50-50, we want to be helping both of those groups as much as possible. We do get calls from relatives of people who are pregnant or planning pregnancies, we get some calls from the general public, media, or, or students who are writing papers and things like that. And then breastfeeding mothers is about one percent of our calls, but that number is increasing and we hope that it will be ever increasing as we hope that people are breastfeeding for a longer time than they are pregnant. And so they, they may have, have questions, during that timeframe as well.

So, the questions that we get from our patients, again 58%, a majority, are about medications, whether those are over the counter or prescription medications. Is this safe to take while I'm pregnant? Is this safe for me to take while I'm breastfeeding or even while I'm planning a pregnancy? we do have a fair amount of, of women who call who have infertility issues so they're worried, is this going to cause it to be more difficult for me to become pregnant? And so those are also questions that we can address. We have occupational agents and this leads to people who are worried about their jobs, can I keep my job? Am I going to get fired? Do I need to move to a different position? Environmental agents are an increasing as, as awareness increases for, for issues in environmental contaminants, we get an increase in the number of calls about, about those agents. Drugs of abuse, maternal illness, herbals, again, this number is creeping up, and radiation still includes, uh, still, is a fair amount of our calls nationally. And, obviously, most of the women that call are currently pregnant, which is an issue because when, by the time they find out that they're pregnant, we've obviously missed some of their, exposure question issues, especially those involving neural tube closure and things like that if they're taking a folic acid antagonist then, then we've kind of missed them if they find out they're pregnant and call us. But, we do get about, anywhere from nine or ten percent of our calls are preconception calls, which is great, and we're hoping to increase that number. Again, breastfeeding and, and paternal exposures are also, things that we, we can address.

Okay, so our goal is to, do these telephone consultations, they are free of charge to these patients, and confidential just like any healthcare record. What we do is we do risk assessment using current data. We have, databases that are available to us that are updated all the time, they're constantly updated, they're available in real-time so they're constantly updated with any new information. I don't know if you guys are, have been, keeping up with the research on SSRIs and neonatal pulmonary hypertension, so those, those kind of issues are immediately updated on the databases that are available to us so that we can give accurate risk assessments with the most recent research. And, and really this last thing is, is our overall goal, was, is to have information to help women and their, their families make informed reproductive choices, as far as, as their medications are concerned.

And so, Otis is an organization of Teratology information specialist, so the specialists as well as the services around the country have collaborated for about the past 20 years, in this national organization. Now, each service does, operate independently, they're, it's not a national funding for the services, uh, and so this is just a collaborative effort at Otis. And, and we have a variety of different people who are involved in Otis, genetic counselors, doctors, nurses, public health, pharmacists, we have people from CDC that are involved, and so it really gives us a broad, perspective so that hopefully we can not only be doing research but affecting policy and things like that.

So, I mentioned the education opportunities, we obviously have professional education within Otis, we have an annual conference that is in June, and this is just a great opportunity for us to collaborate with each other. We're obviously very busy, and our funding is low, so none of us are, have a lot of, of staff, and so what that means is we, we don't get a lot of time to call up each other and say, you know, what are, what are you doing to counsel patients who are exposed to antidepressants? Are you encouraging them to wean off? Are you encouraging them to, to take them while they're breastfeeding? And so this, this conference is invaluable for that. And then we have, joint workshops with the Teratology Society so that, within Otis, within our national organization, we all have a general background of research based science so that we can, incorporate that into our counseling.

Again I mentioned the public education, and we have these fact sheets, and I've included a fact sheet in your handout, it's going to pop-up here in a second. This has really been a great, great opportunity for us to serve the public as well as collaborate with some other organizations. So, they're available on our website for download, and some of these are getting as many as 23 thousand downloads a year. And so, it's just amazing to see, that, that the public really is thirsty for knowledge that's easy to understand, and these are, I've listed the categories, they are separated on the website into categories, and we hope for them, they're almost all translated to Spanish and I would say anywhere from a third to a half

of them are translated into French, for our Canadian services. And so, these are just, great, great, great resources. And so, the one I've included for, in your, handout is, is isotretinoin, Accutane. This is a known teratogen and with the IPledge program, we really have seen a decrease in babies born with, with Accutane exposure, however we still get a few calls a year, just in our service in Texas, from pregnant women who are exposed to, to Accutane, whether that be because they were, not using their birth control and then they, you know, I think we had the last one that called she, uh, she was not taking her birth control 'cause she was divorced and she was not, then she ran into her husband and things, her ex-husband, and she got pregnant. And so, she was, she was worried about her exposure to, to Accutane. So it is still something that, that we, have to address. And a lot of the, the fact sheets that I find to be more relevant than, than this one are, we have one on depression, we have one stress, exercise, things that, that pregnant women are, are worried about, but they may not know how to deal with that worry. And so these, go to the website, look at them, they're, they're fantastic.

Okay, as far as research, okay, thank you, Otis is involved in research which is, which is something that we're always hoping to be increasingly involved in. Basically what we do is registry style research projects, and this works well for teratogen services because the, the women that call our service the families that call our service are inherently interested in pregnancy health because they're worried about their pregnancy health, and so it allows us to involve them in

research that's being done, even if their exposure is non, you know a non exposure, they can be controls, and so it allows them to be participants in, in, in the pregnancy research which we need desperately, women that will be involved in that research.

So some of the research that's going on currently is the autoimmune disease in pregnancy study to determine, about the autoimmune diseases themselves, much like, anticonvulsants, these women often can't go off their medications while they're pregnant and, or choose not to, and so, you have to kind of best manage their care.

And then the discontinuation of antidepressant medication during pregnancy study, I think this is one of our, this is one of our, my favorite of the studies that we're involved in, simply because this is such an issue, we know that so many women are taking antidepressants, and so often, we're very concerned about them going off their antidepressants while they're pregnant. We know that postpartum depression is, is an issue, and so we want them on their medications immediately after their pregnant, and so what this study is doing is comparing women who continue to take their medication throughout their pregnancy with women who discontinue their medication when they find out they're pregnant and then a control group as well, obviously. And this, really we do not have the numbers that we would like to have as a statistical backing for the outcomes of antidepressants during pregnancy, and so this study, I think, is, is very important.

We're also involved in a couple of other studies, West Nile Virus is, we know a lot of viruses are issues during pregnancies, we're not so sure about West Nile, and so this is one where we're registering patients for at Tulane.

Vaccinations in pregnancy, the fact that you have to sign a, a piece of paper that says that you are not pregnant to get a vaccine causes a lot of anxiousness for women who didn't know they were pregnant and got a vaccine. They assume there must be something wrong, if they asked me if I was pregnant, it must mean something bad's going to happen if I am pregnant and I got the vaccine. And, and I would say we get at least a few calls a week, three or four calls a week, from women who are, are very anxious calling from, calling because they're going to terminate their pregnancies because they had a vaccine. And so, this, this really should provide numbers and hopefully get some, some changes in practice as far as this goes.

And then this is a project that we're involved directly in, which is a pilot project that the CDC is doing to show that teratogen services can be used as, an early warning system for potential teratogens because we know that while we, we know a certain number of birth defects are caused by teratogens, a vast majority of birth defects are unknown in the etiology and what is the, the reasoning for it. And so we are hoping that we can be involved, and show that, that because,

again, as I mentioned earlier, these women are, interested in pregnancy, that we can be a way of recruiting them.

And so, this is my closing slide and this is really our goal, empowered by a clear understanding of the reproductive effects of a specific exposure and integration of this information into meaningful answers for an individual of family, our clients are prepared to avoid teratogen exposure when possible, manage medical conditions with the safest known treatment and make informed reproductive choices. And you guys have our website and this are my thanks.