

MCHB/DHSPS April, 2006 Webcast

Preventing Birth Defects with Folic Acid

JOHANNIE ESCARNE: Good afternoon. My name is Johannie Escarne from HRSA. I would like to welcome you to the webcast titled "Preventing Birth Defects with Folic Acid". Before I introduce our moderator today, I would like to make some technical comments.

Slides will appear in the central window and should advance automatically. The slide changes are synchronized with the speaker's presentations. You don't need to do anything to advance the slides. You need to adjust the timing of the slide changes to match the audio by using the slide delay control at the top of the messaging window.

Unfortunately due to technical difficulties we won't be able to take questions from the audience today. But we do apologize.

On the left of the interface is a video window. You can adjust the volume of the audio using the volume control slider which you can access by clicking the loudspeaker icon.

Those of you who selected accessibility features when you registered will see text captioning underneath the video window.

At the end of the broadcast, the interface will close automatically and you will have the opportunity to fill out an online evaluation. Please take a couple moments to do so. Your responses will help us plan future broadcasts in this series and improve our technical support.

Now I would like to introduce our moderator for the day, Miss Adriane Griffen is the acting chair of the national council of folic acid and health promotion partnership at the Spina Bifida Association.

ADRIANE GRIFFEN: We appreciate your patients with us as we get started here. We are going to skip over a couple introductory slides that we would have presented if we had more time. This is folic acid education week. This seminar will focus on four key areas that will deal with folic acid, basic information, folic acid counseling. We'll hear from CDC. We'll also hear from local parents with a personal perspective on living with spina bifida today, the National Council on Folic Acid is funded for the centers through disease controls and prevention. We appreciate their support and thanks to HRSA for sponsoring this broadcast as well. I work for the Spina Bifida Today Association and we manage the National Council on Folic Acid. What I'll do first is go through folic acid 101 piece to be sure all the partners who have joined us today come to the presentation with the same background knowledge. Folic acid we're going to go over four key areas in the outline. Epidemiology, the studies that have led to the Public Health Service recommendations and the impact of folic acid fortification efforts in the United States. Birth defects affect 250,000 individuals nationwide. Of that 3,000 are affected by spina bifida today. The spina bifida is the most frequently occurring birth defects and the first leading cause of infantile paralysis in the United States. \$400 million a year are spent on children born with it in the United States and we wanted to overview evidence that led to the Public Health Service recommendations. The next slide goes over some results of key studies that focus on folic acid and the use of multivitamins to reduce the risk of defects. There were three key studies that led to the Public Health Service lead being -- led to the Public Health Service to the 1992 recommendation and those were the multivitamin trial in the United Kingdom, some research done in Hungary and other research done in the people's

republic of China and it led to the recommendation of all women capable of becoming pregnant should take 4 milligrams of folic acid daily. We highlight the other part of that recommendation which is that if women already have had an affected pregnancy they should consume ten times that amount or 4,000 micrograms or 4 milligrams to reduce the risk of future affected pregnancy. Part of the Public Health Service recommendations recommend a three-pronged approach to encourage folic acid consumption. Improving dietary habits, consuming fortified foods and taking a daily folic acid supplement. Let's talk about the dietary habits. We know if a diet of varied sources is very important. However, it is difficult at times to get the folic acid that you need. We also know that the body absorbs the synthetic or folic acid version easier than the natural version. So we encourage folks to look for fortified foods or to taking vitamin supplements that contain folic acid. In terms of fortified food let's talk about that for a minute. In 1998 the FDA required the addition of folic acid to any food substance that has the label enriched. So this applies to rice, breads, cereals, those types of grain products. It was done to attempt to get folks the folic acid in a general diet. It goes over costs associated with fortification in the United States. The estimates come from CDC. I want to thank them for their contribution here. The annual cost of fortification in the United States is about \$3 million. Now, the estimated cost of direct medical care for spina bifida are \$125 million a year. \$40 is spent in direct medical care costs and -- every dollar of fortification is saved in care costs. That's according to the cost effectiveness analysis. If we were to add the cost of indirect care and include other aspects of daily life of a person living with spina bifida the annual costs are estimated to be \$425 million each year. So in this cost/benefit analysis for every \$1 spent on fortification there are \$120 saved in direct and indirect costs. I thought that was impressive and wanted just to share that with the partners who might at different points need to make the case for fortification efforts. You'll see on the next slide the impact of the fortification of enriched foods and the impact on the blood serum folate

levels. We have had an impact in terms of increasing blood FOLATE since the mandatory rule went into effect in 1998 and you can see the slight rise as it was a recommendation when FDA first recommended it in 1996.

So on the next slide you'll notice two studies that have been recently published. One is from the last January. There has actually been a drop in the level of folate of women in childbearing age. We aren't sure why. We think it may have something to do with the popularity of low carb diets and women aren't consuming some of the food products we worked hard to for the -- fortify. The other article that was recently published highlights the fact that folate consumption is decreasing in populations that already had a low folate status and points toward the need to monitor how we're fortifying and implementing fortification. This leads to our -- the last approach of taking a folic acid supplement.

Taking the folic acid supplement is an easy way to get the recommended daily amount of folic acid and we recognize this is only one component and you aren't off the hook. You still need to have a healthy diet. It's all part of it. If you look at the next slide you'll see the percentage of women who take a multivitamin daily, around 33% and we look to a multi-prong approach. We would like to see the number higher but we have to take into account fortification and diet for women. In conclusion the economic benefits of implementing food fortification with folic acid outweigh the costs. At the present time there are no adverse effects of folic acid fortification and we need to continue and sustain the multi-level approach of encouraging a healthy diet and for -- fortifying food products with folic acid and encourage women to take a vitamin with folic acid. Those are the comments in the folic acid 101 slides I want to share today. Thanks to the workgroup who helped put it together and others that fund the National Council on Folic Acid. For more information on other activities of the national folic acid awareness week I invite you to

check out the website or you can look at the Spina Bifida Association's website. That completes the folic acid 101 outline that I wanted to share with the group.

Next we're going to hear from CDC on the pregnancy risk assessment monitoring system. We'll hear from two speakers. I'll introduce them now and turn it over to them. First we're going to hear from Leslie Harrison. She's an epidemiologist and PRAMS is an ongoing process in different states. Leslie leads a 15 member multidisciplinary team in supporting activities related to ongoing surveillance of maternal behaviors and experiences and research on how the behaviors and experiences affect maternal and infant health. She implemented PRAMS in nine newly funded states. Completed her masters in epidemiology in 1996. Welcome, Leslie. Next I'm going to introduce Denise D'Angelo. She's a program manager with PRAMS. She has worked there since 2001 in that capacity as program manager. She's co-authored several reports and articles and fact sheets and other journal articles relating to and using PRAMS data. She provides technical assistance to Maryland, West Virginia and has worked with some specific PRAMS surveillance system issue with the South Dakota tribal project. In addition to these tasks she works on PRAMS questionnaire evaluation and language questionnaires and other materials. She has completed her -- welcome Denise and welcome Leslie. I'll turn it over to you.

LESLIE HARRISON: Thank you, good afternoon. My presentation I'll -- our presentation is entitled, using PRAMS data to examine unintended pregnancy and multivitamin use. The next slide, please. We'll start with a brief overview of the pregnancy risk assessment monitoring system or PRAMS.

Next slide. PRAMS is an ongoing population-based surveillance system. PRAMS collects data that are state specific and in some instances site specific. Throughout the presentation we'll use state and site interchangeably. PRAMS collects self-reported information on maternal behaviors and experiences before, during and after pregnancy.

Next, please. PRAMS was developed with the goal to reduce maternal and infant morbidity and mortality by impacting maternal and infant health programs, health policies and maternal behaviors.

Next slide. All PRAMS states use a standardized data collection method developed by CDC. The current primary mode of data collection is through a self-administered mail survey. Women who do not respond to the mail survey are followed up by telephone for an interview.

Next slide. The target population for PRAMS is women who have had a recent live birth. These women are identified from birth certificate records and on a monthly basis a stratified random sample is drawn by PRAMS staff at each site. Women are eligible to be sampled between two to six months after the birth of a live infant. The stratified sampling allows states to oversample high-risk groups. For example, states may choose to oversample mothers of low birth weight infants, teen mothers, racial and ethnic minorities and women in particular geographic areas. Next slide. Currently there are 39 sites participating in PRAMS. This includes 37 states, New York City and the South Dakota tribal project. As you can see, nine of the sites, those in lavender, were newly funded in 2006. With the addition of these nine new sites PRAMS represents approximately 75% of all U.S. live births.

Next slide. Today we will be sharing 2004 data with you. This slide shows response rates for PRAMS states in 2004. As you can see, most states did quite well. 27 of 30 states had response rates of at least 70%. The responses ranged from 64% to 89%. CDC PRAMS set the goal of 70% as the minimal acceptable response rate for inclusion of data in multi-state publications or presentations. As such, we will only be showing results from states that achieve the 70% response rate or higher in 2004.

Next slide. Now we will talk about unintended pregnancy.

Next slide. The most commonly cited statistic related to unintended pregnancy is roughly 50% of pregnancies in the U.S. are unintended. This is the accepted national figure which takes into account pregnancies that ended in either a live birth or abortion. It is based on findings from the national survey of family growth which was conducted in 1995 and collected data on events occurring in 1994. The article in which this figure is published is shown at the bottom of this slide. In this we have a nationally represented sample, respondents are interviewed in their homes so the interview is face-to-face from 1973 until 2002 the survey was conducted periodically, once every five to seven years. The survey is conducted through 1995 where surveys of civilian women of reproductive age, 15 to 44, the survey collected information on reproductive history, next slide. So why are we concerned about unintended pregnancy? As I'm sure you are well aware, unintended pregnancy is associated with maternal risk behaviors before, during and after pregnancy. In 1995, the Institute of Medicine published a comprehensive report on some of the behaviors and outcomes associated with unintended pregnancy. Some of which include late entry into pre-natal care, tobacco use, alcohol use, physical abuse and not breastfeeding. Numerous other studies since that time have had consistent findings.

Next slide. Now, let's talk for a minute about PRAMS and unintended pregnancy. In the slides that follow you'll see that PRAMS estimates differed somewhat from the 49% figure often cited from the NSFG. There are several reasons for this. First of all, PRAMS data are not nationally representative. As you saw from the map earlier, PRAMS is now in 37 states. However, data are available most recently for around 27 states. Also as we stated previously, PRAMS samples only women who have had a live birth. PRAMS does not capture information on miscarriages, abortions, fetal deaths and still births. PRAMS finding on unintended pregnancy can be considered reliable among women who deliver live infants. The combined data are also useful but it must be kept in mind that the findings cannot be generalized to other states that don't participate in PRAMS.

Next slide. Now we will show you some data. The questions found on this slide is the PRAMS survey question on pregnancy intention. The question reads, thinking back to just before you got pregnant with your new baby, how did you feel about becoming pregnant? When we calculate the percentage of women who had an unintended pregnancy we're combining those who said I wanted to be pregnant later or then or any time in the future for others. The Healthy People 2010 objective is to increase the proportion of pregnancies that are intended to 70%. Or inversely we could say the goal would be to reduce unintended pregnancy to 30%. Next we'll see some PRAMS unintended pregnancy rates and how well states are progressing toward meeting the Healthy People 2010 goal.

Next slide. In 2004, the prevalence of unintended pregnancy for 25 PRAMS states combined was 42.2% and ranged from a low of 31.4% in Utah to a high of 55.4% in Mississippi. The red line on this and other graphs depicts the Healthy People 2010 goal

for that indicator. Several states are close to meeting the Healthy People 2010 objective which calls for more than 30% of all pregnancy to be unintended.

Next we'll look at trends in unintended pregnancy.

Next slide. Before we talk about the trend data I want to describe the presentation of the graph. Across the X axis we have the years 1997 through 2004. The Y axis depicts the prevalence. It looks at the significant change in eight years, Alaska, Nebraska and West Virginia had significant increases in unintended pregnancy from 1997 to 2004. North Carolina and Vermont had significant decreases. States not depicted on this slide had no significant change in the prevalence of unintended pregnancy during the time period.

Next slide. This slide looks at pregnancy intentions broken down by maternal characteristics. From the graph on this slide we see the prevalence of unintended pregnancy decreased with increasing age. Among teens, the prevalence was 74%. It declined steadily to 56% among 20 to 24-year-olds and down to 34% for those 25 to 34 years of age. It was lowest for those older than 35 or at least 35 and that rate was 26%. We also see that black women had the highest prevalence of unintended pregnancy. 65% versus 36% among whites, 44% among Hispanics, and 41% for those in the other racial group.

Next slide. Again, we look at pregnancy intention by education and insurance. The prevalence of unintended pregnancy was higher among women without a high school education at 57%. It declined to 51% among those with a high school education. And it was lowest with those of more than a high school education where it was 32%. We also

see that women on Medicaid had a higher prevalence of unintended pregnancy, 58% versus 28% for non-Medicaid recipients.

Next slide. PRAMS collects some additional information related to pregnancy intention as well. From the pregnancy intention questions that we showed you earlier, we can break intention down further and calculate the pregnancy mistimed by looking at the women who indicated they wanted their pregnancy later. We can determine the percentage of unwanted pregnancies by looking only at those who indicated that they did not want to be pregnant then or at any time in the future. In 2004, about 32% of women reported a mistimed pregnancy and 10% reported an unwanted pregnancy. PRAMS asks questions regarding partner intention and contraceptive use. The results showed that about 9% of women thought their husband or partner did not want the pregnancy. And only about 50% of women who reported an unintended pregnancy were using contraception when they conceived. Now I'll turn the presentation over to Denise D'Angelo. Next slide.

DENISE D'ANGELO: Thank you, Leslie. Now I'm going to switch gears a little bit from unintended pregnancy and talk about the PRAMS data on multivitamin use.

Next slide, please. We heard earlier from Adriane about the importance of folic acid consumption and the Healthy People 2010 objective is to increase the pregnancies begun with an optimal folic acid level to 80%. The PRAMS survey is shown on the slide. We ask all women during the month before you got pregnant with your new baby, how many times a week did you take a multi-vitamin or pre-natal vitamin. Pills that contain many different vitamins and minerals. The results I'll be presenting on the next several slides show the percentage of women who reported taking a multivitamin four or more times a month prior to pregnancy. This would be the women that answered either of the last two options shown on this slide. Next slide, please. This slide is similar to the graph that Leslie

showed you previously. However, it shows the percentage of women in each state that reported taking a multivitamin four or more times a week in the month before pregnancy. The overall combined prevalence for all states was 35.1%, close to what Adriane mentioned earlier. There was variation among states with the lowest prevalence in Arkansas at 26.7% and the highest prevalence in Rhode Island of 43.6%. As you can see, no state is close to meeting the Healthy People 2010 objective for this goal and indicator.

Next slide, please. This slide shows trends in multivitamin use between 2000 and 2004.

The three states shown on this slide, Hawaii, New Mexico and Utah all experienced a significant increase in the consumption of multivitamins during this time period. States not shown on this slide had no change in consumption during this time period. Next slide,

please. On these next two slides we'll look at multivitamin use by maternal characteristics.

Starting with age in the first graph on the left we see a clear pattern of consumption increasing with age and when we did statistical testing for significance we found women age 35 and older were significantly more likely to take a multivitamin than all other age groups. They took a vitamin about 51% of the time compared to 34% for the 20 to 34-year-olds and about 18% for the teens. There was also significant differences among the racial groups with white women most likely to take a multivitamin compared to all other groups. 41% among the white women, 24% among black, 37% among other, and 24% among Hispanic women.

Next slide, please. This next graph on the left side ties nicely with the slides that Leslie showed earlier. Here we're looking at multivitamin use by pregnancy intention status. As we might expect intention has an impact on multivitamin use. Women with intended pregnancies were significantly more likely to take a multivitamin those with an unintended

pregnancy. Finally in the last graph we see that women with private health insurance were most likely to take a multivitamin compared to women in the other insurance groups either Medicaid or with no insurance. Those rates were 45.9% for the privately insured, 21.4 for the Medicaid women and about 19% for women with no insurance.

Next slide, please. So just to recap and summarize the 2004 PRAMS data we presented today we saw that unintended pregnancy is prevalent. 42% overall with variation among the states. We also saw that only about half of women with an unintended pregnancy were using contraception when they conceived their new baby. Regarding multivitamin use we found that the use before pregnancy is overall around 35% and it was significantly lower about women with unintended pregnancies compared to women with intended pregnancies. 31% versus 46%. Next slide, please. While we enjoy sharing the results from the data analyses we try to emphasize the importance of transforming the data into something more. One important objective of PRAMS is to use the data to impact public health programs and policies in the area of Maternal and Child Health. Examples of ways that the PRAMS data can be used to do this are shown here. It can be used to conduct needs assessments, justify requests for resources and modified programs and policies related to maternal and infant health. It can be used to monitor progress towards meaningful performance measures as we demonstrated in this presentation.

Next slide, please. Given that one of the primary objectives of PRAMS is to use the data to facilitate public health action we wanted to share an example featuring the New Mexico Department of Health work to address unintended pregnancy in their state. Their staff analyzes the data something the prevalence in numbers of unintended pregnancy. Contraception use at the time of conception and the cost of unwanted pregnancies to Medicaid and passed the information on to various stakeholders including others in the

Department of Health, planned parenthood of New Mexico, the New Mexico pharmaceutical association and the University of New Mexico.

Next slide, please. With the stakeholder support the data were used to focus on increasing the visibility on the importance of access to emergency contraceptives or ECCs.

Next slide, please. In early 2001 the New Mexico board of pharmacy and the New Mexico pharmaceutical association requested that the legislation amend the pharmacy act to allow the board of pharmacy to develop protocols for prescribing ECCs by pharmacists. The law was passed and signed by the governor and protocols were subsequently developed.

Next slide, please. PRAMS data on unintended pregnancy for house bill 119 requiring hospitals to provide indication and ECP treatment to rape survivors. This bill became a law in 2003.

Next slide, please. Finally, a PRAMS newsletter was created to discuss preconception issues including pharmacy protocols. The New Mexico workgroup has used the newsletter to educate pharmacists, physicians and other health professionals across the state.

Next slide, please. We hope we've given you a sample of what PRAMS is and what the data show and how the data can be used. We'd like to mention our website where you can find more information regarding PRAMS such as our surveillance reports, links to surveillance summaries, the most recent was published last month on preconception

health. There is also information on the website about our mini proposal process to request data for folks who would like to analyze raw data. You can find lists of all current PRAMS questions on the website. We are now in the process of revising our questionnaire to put a new version in the field in 2009. States will be selecting questions for their new survey in the next month or so. So if you're interested in what a particular state might be thinking of putting on their survey you can find contact information on the website as well for all PRAMS coordinators.

Next slide, please. We'd like to acknowledge the members of the PRAMS working group from all the PRAMS states. Without their hard work and the work of all the PRAMS staff we wouldn't have the data to share with you today. Next slide, please. Finally, please see our contact information and don't hesitate to call or email us. Thank you very much.

>> Thanks, Denise and Leslie. We appreciate that. The workgroup that put together today's seminar was interested in hearing how the data and multi- vitamin use related. Next we're going to hear from Catherine Ruhl speaking to us about folic acid counseling. She's the associate director for women's health programs at the association of women's health, obstetric and neonatal nurses in Washington, D.C. She has practiced as a certified nurse/midwife for 20 years working with women from a variety of backgrounds. She obtained her bachelor in nursing from the University of Kansas and Master of Science in nursing from the University of Illinois in Chicago. She coordinates professional nursing education programming for A1 and represents A1 to a variety of national organizations including the partnership to end cervical cancer and CDC's select panel on preconception care. Her interests are policies and practices for optimizing women's health across the life span. Catherine.

CATHERINE RUHL: Thank you, Adriane. I want to begin and really put out a wakeup call to providers before we get into specific folic acid counseling approaches. My first slide will show a survey of providers that was nurses, nurse practitioners, nurse midwives, physician assistance, OB/GYN physicians and family medicine physicians. The good news was that 97% of the providers did know that folic acid could prevent neural tube defects. This awareness did not equate with knowing about dosages or necessarily counseling women. 42% of all the providers surveyed did not know the recommended folic acid dose for primary prevention of 400 micrograms. 70% did not know the dose to prevent recurrence, the dose of 4,000 micrograms. Providers who took multi-vitamins themselves were twice as likely to recommend multivitamins to patients. Perhaps surprisingly only half of providers were aware of the 50% unintended pregnancy rate in the U.S. Most underestimated that. The take home points from this survey published in the Maternal and Child Health journal is for providers to review their folic acid dosages and counsel all the women they see of childbearing age.

In the next slide I want to talk about how we can get motivated about folic acid counseling. First off, we know that it works. The benefits are proven. Secondly, for women taking folic acid can be easy and inexpensive and providers it's an easy and brief message for providers to communicate. We know that women need to increase their consumption so our advice is needed and it will make a difference. And really, again, we have to think about that 50% of pregnancies being unintended when we think about how we need to counsel all the women we see of childbearing age.

Moving into my next slide, let's look at the Tenets of successful counseling. We want everyone on our healthcare team doing that. We want to repeat our messages whenever we can and have some message saturation to make sure we're really reaching women.

Let's look at the next slide about how we can consistently get the message out. We went to in-service, our entire teams, about the messages we'll be communicating and make sure that it is risk-based advice we're giving women depending on what their situation is. I want to mention that webinar will be archived by the end of the week, I hear. That could be an important adjunct for in-servicing your team and we don't want to forget to in-service new staff perhaps during their orientation.

The next slide I've listed the various occasions when we encounter women that we can get out the message about folic acid. Certainly annual exams, family planning visits, postpartum, GYN, pre-natal visits, post pregnancy loss, a good one to remember. Medical visits especially if we're seeing women who are taking folic acid inhibiting medications or have conditions that put them at higher risk. How do we saturate our settings with the message of folic acid?

That's on the next slide and, of course, I don't mean we have to wallpaper our walls with posters about folic acid but there is a lot of creative things that can be done. Annual exam reminders can include the messages. Telephone hold lines I'm sure some of our patients are on hold when they schedule appointment and they can get the message. Educational prescription pads with folic acid action reminders can be used. Posters should be strategically placed when we use them. Find the best location in your setting to really reach women using, of course, messages that will resonate with them and in their appropriate languages. And remember to keep brochures well stocked for providers. The next slide I listed some health education opportunities. If you have a pregnancy program that's an excellent time to get the message in. Pre-natal classes, breastfeeding classes, wellness classes and nutrition visits are also good opportunities. Moving on, a folic acid advocate can be your point person in your setting to get out the message. This person

reviews folic acid messages and the program that you have with your new staff. They can maintain the stocks of educational materials for patients. Identify new educational materials including posters and brochures. And update staff on any new research relating to folic acid and neural tube defects. Moving on to the next slide, some general counseling tips. First off, be brief. Remember, this does not have to seem like a burden or take a large part of your day or even a really small part. You can be brief. You're trying to get out this message for all women of childbearing age because it prevents neural tube defects and is easily obtainable with vitamins or in food sources. Secondly, don't assume that your other staff members, that your colleagues have discussed folic acid with women. You be the one to do it today. Encourage multivitamin use for all women and remember to use pictures as something that can really stay with women. A food that contains fortified foods.

>> Moving into the next slide, why multivitamins? We've touched on that a little bit but just to review, most women don't eat enough fortified and folate-rich foods. A multivitamin every day is the easiest way to get the folic acid. The body absorbs folic acid better than folate. They're inexpensive and name brands or generics are both fine. We encourage women to take multi-vitamins by linking them to another daily activity. Reassure women that multi-vitamins have not been known to increase hunger or gain weight which are very common statements that women may have about multivitamins.

In the next slide I list some fortified foods and folate-rich foods. We've covered these already but I want to encourage that the fortified foods you really need to check the labels to see which cereals, for instance, offer the very largest amounts of folic acid and you want to think about what your population commonly eats. That can help you really make

your advice specific to the women you see. Moving along, you know it's not enough just to talk about where you can find folic acid. You want to really help women understand why all women of childbearing age should take folic acid and stress that there would be a 70% reduction in neural tube defects if all women took the 0.4 milligrams daily. In the next slide I want to look at some myths about folic acid but some common kinds of excuses that women will give. I think that women really often, they can hear the message but they don't really think that they personally are at risk. One of the most common things people think if it's not in their family they aren't at risk. You can remind women that 95% of neural tube defects occur without a family history. They're not linked to older maternal age. Eating well has not been shown to be enough for the majority of women. Neural tube defects cannot be cured so prevention is key. And that just because a woman is not planning pregnancy, that does not mean that she shouldn't think about taking folic acid as we've seen because 50% of currently pregnant women weren't intending to be pregnant, either. It's helpful to be aware of the women who are at increased risk for NTDs and on the next slide I list that groups you want to think about are women with certain medical conditions, taking folic acid-inhibiting medications, the demographics of NTD risk and those with a history of NTD.

Let's look at the next slide, the medical conditions. Those with poorly controlled diabetes have a 1% risk for NTD. A BMI of over 30 doubles the risk of NTD. And if women are on certain medications used for arthritis or cancer they have an increased risk. Moving into the next slide we have a list of the general categories of medications that may put women at risk. I listed a website at the bottom that will tell you what specifically -- what medications there are. Anti-seizure, anti-cancer, antibiotics, certain sodium channel blocking potassiums about diuretics. Certain anti-inflammatories and certain hypoglycemics.

In the next slide we look at the demographics. In the United States Hispanic women are 1 1/2 to 2 times more likely than others living in the U.S. to have NTDs. Non-Hispanic white are next and non-Hispanic black is third and in general I believe as we've seen with other data, a lower socio-economic status has a higher rate. Now, what about women with a history of NTD? If you look at the next slide, those with the increased risk for reoccurrence have had a previous child with NTD or a previous NTD-affected pregnancy or an NTD themselves. On the next slide as far as counseling these women, they should be counseled to start a prescriptive 4,000 micrograms of folic acid one to three months before pregnancy continuing in the first trimester. This can reduce the risk of repeat NFDs by 75%. And they should be advised not to just double or triple or increase their multivitamins but to have the prescription of additional folic acid.

In the next slide I just want to touch on also that these women should be encouraged to make proactive plans for future pregnancies if they desire them. Stress the importance of reliable birth control methods until they're ready for another pregnancy and explain that not even taking the increased dose would guarantee a baby without an NTD but would decrease the risk. So just wrapping up, in the next slide I review goals for your healthcare setting. You want your whole team to understand the benefits of folic acid to women and families. And based on this understanding, implement a comprehensive folic acid education program for all women of childbearing age. You should measure the effectiveness of your program regularly and alter it as needed to suit your population's need.

Next slide. You've done your job if the women you see are well-informed about the benefits of folic acid for their specific situation. Folic acid myths are dispelled, women are

aware of sources of folic acid and women are empowered to make proactive choices about folic acid use. Ultimately they're the ones who have to insure their consumption.

Just to briefly place folic acid in the larger picture of preconception health in the next slide, folic acid is an integral piece and really provides an excellent example of how we should be striving to maximize women's health in the reproductive years in terms of family planning, nutrition, physical activity, disease prevention and disease treatment. And next slide. The hope is in optimizing health in the reproductive years it will result in better health for a woman throughout her life, even into her older age and better health for any children she decides to have for their entire lives. I have included in the next two slides some additional folic acid resources and I thank you all for your time.

>> Thank you, Catherine, we appreciate your real world examples of folic acid counseling and we hope that partners are able to use them in their practices. Thank you. Next we're going to hear a personal perspective from Eileen Carlson. She is both a parent of a son who has spina bifida and also has a brother with spina bifida. Eileen has been very active with our local chapter here as part of the spina bifida association's greater Washington chapter.

Eileen has her son, Sean, is 10 1/2. I can't believe he's 10 1/2 already. I met Sean a few years ago at a family picnic in the summertime. I remember him scooting around by the lake on his bicycle. He's in fifth grade now at the Blessed Sacrament school here in Washington, D.C. and Eileen's, brother, Danny, 40 years old lives independently in the Houston, Texas area. She has been involved in speaking and writing about spina bifida for several years including testimony to the food Food and Drug Administration. The vice president of the local chapter of the Spina Bifida Association and involved in parent

support groups. Registered nurse and an attorney, Eileen is an associate director for government affairs at the American nurses association. Welcome, Eileen.

EILEEN CARLSON: As Adriane said I have a brother named Danny who is 40 who has spina bifida. He lives independently. He drives and never walks and received an associate degree in art but he's never been able to find employment. My son, Sean, is in fifth grade. Takes regular classes. He plays challenger T-ball, just started playing sled hockey, learning the trumpet and loves his friends and sports. He walks with a walker and ankle braces. I would like to talk about, as you may be aware, spina bifida is the most common neural tube defect.

Some of the -- even though every person who is born with spina bifida with the most serious form, every person is different. There are some common aspects which you may or may not be aware of. First of all, the spinal cord is malformed when the child is born. It is exposed and in utero and after birth it leads to severe damage. There is often hydrocephalus, an excess of spinal fluid on the brain which leads to shunting. They can become blocked and infected and it can affect cognitive and mental abilities along the line. There is almost universally impairment of bowel and bladder function. Usually incontinence. There is weakness or paralysis of the lower limbs and children or individuals with spina bifida of this nature may ambulate or may not. Some who ambulate early lose that ability as they grow older. There are orthopedic deformities related to innervation that can require surgery for standing and ambulation as well. Later on, there can be tethering of the spinal cord.

Every child with spina bifida has a tethered spinal cord and it can cause nerve damage later on and lead to surgeries. Also it can cause scoliosis. In some children who are

severely affected there can be breathing and swallowing issues and it can be sometimes incompatible with life. In many individuals with spina bifida, the vast majority, there is a form of learning disability especially executive functioning. Different levels of cognitive impairment and in some children there are some moderate to severe developmental delays. There are also other neurological effects such as difficulties with fine motor skills, difficulties with visual acuity and difficulties with visual perception. Okay.

And I just kind of wanted to outline the challenges. I usually just sort of tell my story and history but I thought since you all are healthcare providers and working in healthcare policy I thought I would just kind of summarize and some of this is based on my own experience and some of it is based on the experiences of my friends and fellow parents and families. The first category I would say of major challenge is just the enormous amount of time and effort that goes into just medical appointments and surgeries. Children with spina bifida, it's not unusual to have dozens of surgeries. And especially during the early years just taking your child to appointments. You see neurosurgery, urology, orthopedics, physical and occupational therapy and others. That's not going into speech therapy and other types of therapy that might -- an individual child might need.

There are also a huge part of time and effort is spent preventing skin breakdown and treating it when it does occur. It's like having diabetic skin. They don't feel as well. They are much more prone to not only skin breakdown but actually fractures and injuring themselves and burns and things like that. So you can imagine what the toll this takes on time and energy, not just for the family, but also from the child's social development. And healthcare professionals sometimes have a hard time taking this into account. That's something to keep in mind because the family, especially if there are siblings involved, the parents and extended family need to spend time and develop relationships and -- towards

-- just spend time with the siblings and give them attention as well. And the child with spina bifida also needs time to just be a child.

Another big challenge is cost, which we talked about a little bit. Health insurance, whether or not the family has health insurance, what sort of job the parents may be able to find that provides good health insurance. Some families are able to receive assistance through SSI, Medicare and Medicaid, but the needs of caring for the child can limit the parents' ability to work and to have gainful employment. There is difficulty finding childcare that's adequate, appropriate or even accepting of the child's needs. Just to give you one example, when my son was born the hospital bill alone for him in 1997 was \$200,000. His latest leg braces, which are KAFOs, knee ankle foot or thoet is, those were \$10,000. Education challenges are huge. Thank goodness we have the IDEA. Most children with spina bifida get IEPs. Our son got accommodation because he didn't need special education. Learning disabilities can be a huge issue. Executive functioning is usually impaired. Writing ability, reading ability, memory retention, those can all be issues. And let's not forget that many school facilities are not physically accessible to some of these children. It's -- that's a commonly overlooked problem. And the availability of aides, someone to assist with toileting and other needs in our current environment where many schools don't have a school nurse, unfortunately. Then there is time spent on school for therapy that may or may not be available. Physical therapy, OT, speech and language, other services. Some families kind of give up and do homeschooling, which I can -- which is understandable when a child's medical needs are severe but that also limits socialization.

Other challenges include just the need for extra care at home. Thank goodness one of the major medical developments in the care of spina bifida is the implementation of CAC,

which is catheterization that's clean, not sterile and that's really saved a lot of lives, a lot of cases of spina bifida couldn't void and there would be reflux to the kidneys. It has to be done every few hours. A lot of children require assistance. They require bathing assistance, assistance with self-care, dressing. It takes an extra effort to provide them social opportunities. They can't help with chores as well as other kids, although there is a lot of effort being made to encourage parents to give them chores and develop responsibility and independence. Physical barriers to accessibility in the community, like I said schools, the homes of friends, relatives may not be accessible especially if a child uses a wheelchair. A lot of the time, which is very common with individuals with spina bifida.

Public places may not be accessible such as libraries, shopping, restaurants, parks, recreation. Even your own neighborhood may not have sidewalks. Your own home may not have stairs. It may not have accessible bathrooms and kitchens. These are major challenges. Social development is a huge issue. How can a child have a normal social development when they're spending so much time in the hospital and in doctor's offices when their friend's houses are not wheelchair accessible and they're incontinent and can't participate in sports and many other school activities? It's -- it's a big effort to get over these things. And then finally, one of the things that we probably don't talk about enough is the emotional and psychological effects and challenges. Even for the individual with spina bifida may be subject to depression. The parents and siblings, psychological health is impacted severely as well. The good news is things have gotten a lot better especially since my brother was born 40 years ago. Like I said, medical care, catheterization, their new medical treatment and surgeries such as bladder augmentation. Other types of procedures that allow people with spina bifida even children to give themselves enemas through a STOMA. And actually the development of spina bifida clinics where there is

coordinated care and the healthcare professionals work together as a team. That can be very, very helpful. Education is improved.

There are now quite a few college programs across the country that have special programs for students with learning disabilities and special programs for students who are physically disabled as well. In recreation there are sports available. In physical barriers thanks to the Americans with Disabilities Act we're making a lot of progress as physical accessibility. We still have a long way to go. I would say the biggest area that people are really focusing on nowadays is with jobs and employment because we have a whole generation of adults with spina bifida and it is just not easy to find a job and to convince -- you have to get in the door for the first part and then you have to convince somebody that you're healthy and competent and it is hard to get experience at the ground level to get a decent job. Social acceptance of differences, we have a long way to go there.

There are still various surgical and medical approaches to a lot of problems with spina bifida, including orthopedic problems. We need more improvement in education and we need -- a lot of families need additional financial support. But one of the things I would like to say is there are certain advantages of having a child with spina bifida. One of them is the resources like the spina bifida association where there are support groups and educational conferences and other resources. You meet wonderful parents and families and very giving healthcare professionals. The special relationship that we have with our kids. And the lessons that they teach us that we all need to help one another and that the human spirit truly can triumph over circumstances. Then I just would like to talk a little bit about what can healthcare professionals do to help. First of all, be understanding of the families and the child's non-medical needs including the cost in social and school priorities, a need for a normal life and to look at the big picture. To be sensitive to the

feelings of the child and the family, especially when there is bad news given. Be available as a resource. There are some wonderful clinic nurses and occupational and physical therapists and even some doctors, too, who are available any time day or night. Provide evidence-based care. Fully explore and communicate all risks and possible outcomes. And respect the parents' roles as caretakers because sometimes they are caretakers for life.

>> Thank you, Eileen. Appreciate that. It is so important for all of the partners of the National Council on Folic Acid to remember what we do what we do. Birth defects happen to real families and we can all earn our keep and tell all the women we know of childbearing age to make sure they are getting the folic acid that they need. It's important to share stories like that. Thank you so much. I do want to remind all of the partners who have tuned in today that the broadcast will be archived on the HRSA website mchcom.com available later this week. Thank you so much for tuning in today. Sorry we cannot do questions and answers at this time. However, if you do have any follow-up questions, you can check out the folic acid council's website. I would invite you to also check out the Spina Bifida Association's website. Thank you so much and I'll turn it back to Johannie for any wrap-up.

JOHANNIE ESCARNE: Thank you, Adriane. On behalf of the Division of Healthy Start and perinatal services I would like to thank our presenters and the audience for participating in the webcast. I apologize for the technical difficulties in not being able to have questions. If you submitted any questions I'll try to get them to the presenters and possibly be able to get those answers for you. I would also like to thank our contractor, the Center for the advancement of distance education at the University of Illinois at Chicago School of Public Health for making this technology work. Today's webcast will be

archived and available in a few days on the website mchcom.com. We encourage you to let your colleagues know about the website. Thank you and we look forward to your participation in future webcasts.