EDUCATION AND RESEARCH UPDATE

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SURGEON GENERAL REPORTS "IN 2005, 430 NEWBORNS DIED FROM SIDS CAUSED BY SECONDHAND SMOKE."

The Health Consequences of Involuntary Exposure to Tobacco Smoke
A Report of the Surgeon General, Department of Health and Human Services, 2006

According to US Surgeon General, Richard Carmona, there is no safe level of second hand smoke. Only smoke free buildings and public places truly protect non-smokers from the hazards of breathing in secondhand smoke. The Surgeon General reports that approximately 126 million non-smokers are exposed to secondhand smoke or "involuntary smoking" that puts the population at a significantly increased risk of death from heart disease, lung cancer and other illnesses. "The debate is over. The science is clear. Secondhand smoke is not a mere annoyance but a serious health hazard," Carmona said.

In a letter from Julie Gerberding, MD, Director of Center for Disease Control, she writes, *"In 2005, it was estimated that exposure to secondhand smoke killed more than 3,000 adult non-smokers from lung cancer, approximately 46,000 from coronary heart disease and an estimated 430 newborns from Sudden Infant Death Syndrome."*

This 2006 report from the Surgeon General documents that among children younger than age 18, an estimated 22% are exposed to secondhand smoke in their homes.

Other findings from this study included:

Children of smoking parents appear to have measurable but small differences in pulmonary function studies when compared to children of non-smoking parents.

Children of parents who smoke have increased frequency of acute respiratory illnesses and infections before 2 years of age and physician diagnosed bronchitis, tracheitis and laryngitis when compared to children of non-smokers.

Children of parents who smoke have an increased incidence of hospitalizations for bronchitis and pneumonia during their first year of life when compared to children of non-smokers.

Finally, as written in Chapter 5 Conclusions of this study:

"The evidence is sufficient to infer a causal relationship between exposure to secondhand smoke and Sudden Infant Death Syndrome."

For more information go to www.cdc.gov/tobacco to access the 400 page document.

BLAGOJEVICH ADMINISTRATION ANNOUNCES ILLINOIS TO SCREEN NEWBORNS FOR CYSTIC FIBROSIS *ANNOUNCEMENT PUTS ILLINOIS IN THE TOP TIER OF MARCH OF DIMES' NEWBORN SCREENING REPORT CARD*

CHICAGO – On behalf of Governor Rod R. Blagojevich, Dr. Eric E. Whitaker, Director of the Illinois Department of Public Health, announced today at Children's Memorial Hospital the state is moving forward with plans to require screening of all newborns for cystic fibrosis. After sickle cell disease, cystic fibrosis is the most common life-shortening genetic disorder in the U.S.

"By screening newborns for cystic fibrosis, we can help babies get the treatment they need and the chance to live longer lives," said Gov. Blagojevich. "Every child deserves the opportunity to grow up healthy. That's why we created our *All Kids* program for parents who are working hard to make ends meet but still can't afford private health insurance for their children and that's why screening newborns for cystic fibrosis is so important."

Cystic fibrosis is a genetic disease that causes thick, sticky mucus to build up in the lungs and digestive system and other organs of the body. This leads to chronic lung infections and difficulty in digesting food. Treatments include pancreatic enzyme supplements to help with absorption of calories and nutrients, high calorie and high fat dietary supplements and other treatments to clean the airway and improve lung

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WHY IS A POST MORTEM EXAMINATION IMPORTANT WHEN A CHILD DIES SUDDENLY?

By Henry F. Krous, MD
Director of Pathology, Children's Hospital – San Diego
Professor of Pathology & Pediatrics, University of California, San Diego School of Medicine
Director, San Diego SIDS/SUDC Research Project

Stricken with grief, parents experiencing the sudden death of their child are often and understandably reluctant to have a post mortem examination performed on their son or daughter. And yet, sudden deaths of individuals of any age and without apparent explanation are under the legal jurisdiction of the medical examiner who must determine the cause and manner of death. In order to do this, the medical examiner must perform a post mortem examination as well as be knowledgeable of the medical history and circumstances of death.

Perhaps it will help to begin with a basic description of the post mortem examination. It begins with a review of the medical history of the infant or child who has died. Secondly, it also involves a careful evaluation of the circumstances of death, including a reconstruction of the site where the infant or child was found apparently lifeless. The post mortem examination itself is the evaluation of the external appearance of the body and internal organs. It is undertaken much like an operation, but by a pathologist rather than a surgeon. In addition to the anatomic studies, ancillary studies are typically done as well. They may include post mortem X-rays, microbiology, toxicology, metabolic screening and chemistry evaluations. The dignity of the body is always maintained and disfigurement does not occur, therefore, funerals of choice can be performed.

With this background, what advantages accrue to the parents and other survivors of these children when a post mortem examination is performed? There are many and they have long term implications. First, when supplemented by the medical history and circumstances of death, the post mortem examination is the best way of determining the cause of death. Without the examination, the medical examiner does not always have enough information to make this determination unless there is something lethal about the scene, such as a toxic environment, where the child died.

Secondly, some of these parents may experience unwarranted guilt as they wonder if they may have caused the sudden unexpected death of their infants and children especially when they lack an understanding of the cause of death. Therefore, knowing why one's child died as the result of the post mortem examination can facilitate healthier grieving over their loss by allowing parents to focus on the wonderful memories of his or her life rather than agonizing over the unknown. When parents do not know what caused their child's death, they may imagine terrible, but unrealistic scenarios, such as "did my child suffer great pain before dying?"

Third, the knowledge gained from post mortem examinations of every infant and child is vitally important for every pathologist who performs them. It is not only through experience, as well as continuous study that we as physicians and pathologists improve our personal knowledge and expertise in complex areas of medicine, and that includes especially the topic of sudden unexpected death in childhood and infancy.

Aside from the valuable experience and expertise accruing to pathologists and other physicians, diagnoses derived by post mortem examinations are critical to the accuracy of vital statistics. Vital statistics are the basis for the allocation of health care resources by governmental agencies, such as the National Institutes of Health, and private sources, such as the CJ Foundation for SIDS. In this regard, the CJ Foundation is the only organization that funds research directed towards sudden unexplained death in childhood (SUDC).

Fourth, scene investigations and post mortem examinations are critical to research into SUDC. In comparison, for example, risk factors for SIDS were identified long before the underlying mechanisms involved in the cause of death have been clarified. Public education campaigns using epidemiologic data about these risk factors have led to dramatic reductions in SIDS rates with many fewer infants dying today compared to just a few years ago. We have no reason to doubt that the same thing will not happen with respect to SUDC.

With this in mind, the value of communication between families of SIDS infants and SUDC children and the medical examiners and coroners who investigate these children's deaths can not be overestimated. Face to face meetings are encouraged for several reasons. The autopsy report will never answer every question that a family will inevitably have. And, these reports will nearly always include medical terminology that may not be understood by the families. In contrast to telephone conversations, face to face conversations allow the medical examiner to "read" the nonverbal conversation of the families, thus providing the opportunity for clarification of confusing issues. The medical examiner's concerns for the family as they grieve the loss of their children are better expressed as well. In this regard, the medical examiners are fulfilling a role similar to clinical physicians in their interactions with their patients and their families.

Let me conclude with my personal experience regarding the attitudes of families whose infants and children have died during the past 30 years. During the time frame surrounding the infant or child's death, some parents have been very reluctant to have a post mortem examination performed on their child. This is understandable. At times, these objections may center on religious or cultural beliefs. Other parents may simply object to having the procedure performed for aesthetic reasons. Many of these objections can be mitigated by a careful explanation of what an autopsy is and what is to be gained will hopefully mitigate some of these objections. It is particularly important for parents to understand that a cause of death cannot be reached without performance of a post mortem examination, which in some cases may involve only ancillary studies.

Parental attitudes and healthy, successful grieving six months or more after the child's death have always favored performance of the post mortem examination. That is to say, I have never met a parent whose child died some months before my conversation with them that regretted having the autopsy performed. Conversely, in those cases where the examination was not undertaken, the parents are left with an irresolvable uncertainty regarding the cause of their child's death and have invariably regretted that the post mortem examination was not performed.

Those parents, whom I have met throughout my professional career whose child was examined were extremely grateful and rewarded that it had been undertaken. They have been able to reach closure in a more satisfactory fashion with knowing why their child died.

In selected cases, genetic disorders were discovered only during the post mortem examination. This information is vital to families planning future pregnancies and better protects surviving family members.

Is should be noted that a post mortem examination does not always identify a cause of death. Nevertheless, the parents can be comforted to know that the effort was made. But is also must be remembered that these cases also provide information and materials that are important to vital statistics, education and research. There are many examples of this, perhaps the most obvious being the identification of risk factors for SIDS. Even though the exact cause of SIDS remains unknown even today, education of the public about what infant care practices should be avoided has resulted in dramatically lower SIDS rates throughout all developed countries of the world. Parents can share in this success by knowing that the post mortem examination of their children facilitated this progress.

NICOTINE METABOLIZING GENES GSTTI AND CYP1A1 IN SUDDEN INFANT DEATH SYNDROME

Rand CM, Weese-Mayer DE, Maher BS, Zhou L, Marazita ML, Berry_Kravis EM. 2006. AmJ Med Genet Part A 140A:1447-1452

Exposure to tobacco in the prenatal and postnatal period has been identified as a risk factor in Sudden Infant Death Syndrome (SIDS). Polymorphisms (naturally occurring variations in the DNA sequence that are useful genetic markers because they allow researchers to distinguish between DNA of different orgins) in both GSTT1 and CYP1A1 genes have been reported to have an impact in the metabolic detoxification process for cigarette smoke and have been associated with low birthweight. In looking at the polymorphisms in these genes, it is hypothesized that there may be a susceptibility to adverse health outcomes and may be associated with SIDS in Caucasian and African American infants.

106 SIDS cases, identified by a diagnosis from University of Maryland Medical Examiner in the University of Maryland Brain and Tissue Bank, were reviewed. 7/106 indicated prenatal and postnatal tobacco exposure. 106 control subjects were matched for ethnicity and gender and each family history revealed that no family member for three generations had a diagnosis of SIDS, Hirschprung disease, Congenital Central Hypoventilation Syndrome, Apparent Life Threatening Event, primary disorder of autonomic nervous system dysregulation or tumor of neural crest orgin.

Tobacco exposure, both to the developing fetus and in the postnatal period, has been shown to be a modifiable risk factor for SIDS. Genetic traits that alter how effective the body is at metabolizing toxins that are encountered through tobacco exposure may increase the risk of SIDS. No association was found with know mutations in genes that are associated with nicotine metabolism and infant who died of SIDS; the problem was the sample of SIDS infants with known cigarette exposure was small (only 7/106) and so no one can rule out that there may or may not be an association until a larger sample of smoke exposed SIDS infants is studied The largest limitation of this study is the lack of exact tobacco exposure pre and postnatally in the SIDS cases. A prospective study of SIDS cases with nicotine exposure history is necessary to resolve the relationship between nicotine metabolizing genes and SIDS.

BLAGOJEVICH ADMINISTRATION ANNOUNCES ILLINOIS TO SCREEN NEWBORNS FOR CYSTIC FIBROSIS

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function.

“Fifty years ago, people suffering with cystic fibrosis typically didn’t live long enough to go to school,” said Dr. Whitaker. “Today, people with cystic fibrosis are living into their 30s, 40s, 50s and even longer thanks to aggressive treatments. By screening newborns, treatment can begin immediately and help prolong lives.”

Cystic fibrosis is hereditary. More than 10 million Americans are unknowing, symptom-free carriers of the defective cystic fibrosis gene and most are not aware of a family history of cystic fibrosis. It takes two copies of the gene, one from each parent, for a child to be born with cystic fibrosis. About 1,000 new cases are diagnosed each year in the U.S.

The Illinois Department of Public Health (IDPH) will immediately initiate changes to the Administrative Rules governing newborn screenings to add testing for cystic fibrosis. One of the proposed changes will be to raise the current newborn screening fee from $47 to $56 to cover the costs of adding cystic fibrosis to the newborn screening panel. The fee will help cover the cost of screening equipment plus staff, and will be comparable or lower than fees charged by other states performing similar newborn screenings.

The proposed rule changes will be submitted to the Joint Committee on Administrative Rules for approval which can take anywhere from three months to a year. Once approved, a two to three month small-scale testing will be conducted to enable the IDPH Newborn Screening Laboratory and follow-up staff to gain experience. Full scale, statewide testing of all newborns will be implemented upon conclusion of the small scale-testing, which is expected to be around July 2007.

“I commend Dr. Whitaker for taking action to initiate changes to the Administrative Rules,” said Rep. David E. Miller (D-Dolton). “I am pleased that the state will require newborn testing for Cystic Fibrosis. Through my work in medicine as a dentist, I know the importance of early diagnosis. This newborn screening will help save families precious time to start treatment if their baby is diagnosed with cystic fibrosis.”

“The Illinois Department of Public Health and the State of Illinois have acted to improve the health of hundreds of children by beginning implementation of universal newborn screening for cystic fibrosis,” said Children’s Memorial Hospital Cystic Fibrosis Center Director Dr. Susanna McColley. “Research has shown that infants diagnosed with cystic fibrosis as newborns have better health than those diagnosed when they develop symptoms of cystic fibrosis. There is also a reduction of the cost of health care because many complications of cystic fibrosis can be prevented or lessened by early care and early detection. Newborn screening, along with the rapid advances in cystic fibrosis care, will lead to an increased length and quality of life for people with cystic fibrosis. I would like to acknowledge the leadership of the Cystic Fibrosis Foundation and the March of Dimes, and to thank IDPH and the State of Illinois for implementing this important program,” said Dr. McColley.

Currently, 14 states are providing cystic fibrosis screenings for newborns. Five states have passed laws to require testing, but not yet implemented the tests, and most other states are working to add cystic fibrosis to the newborn screening panel.

Cystic fibrosis is one of 29 disorders the March of Dimes recommends every baby born in the U.S. be screened for. With today’s announcement that Illinois will begin screening newborns for cystic fibrosis, the state becomes one of only six states and the District of Columbia that screen for all 29 disorders. The March of Dimes Newborn Screening Report Card groups states into three categories – red state, which screen for fewer than 10 conditions; yellow states, which screen for 10-20 conditions; and green states, which screen for more than 20 conditions. Illinois is a green state when it comes to the March of Dimes Newborn Screening Report Card.

“Newborn screening is a March of Dimes top priority, so we are delighted with the addition of the cystic fibrosis screening. Now all babies born in Illinois will receive the critical early identification and

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STATE CHILD CARE REGULATIONS REGARDING INFANT SLEEP ENVIRONMENT SINCE THE HEALTHY CHILD CARE AMERICA - BACK TO SLEEP CAMPAIGN

Rachel Moon, Lauren Kotch, Laura Aird Pediatrics 2006; 118;73-83

Although there has been an overall decrease in SIDS deaths throughout the United States, the number of SIDS deaths that occur in child care settings remain constant at approximately 20%. The AAP's Healthy Child Care America began it's own Back to Sleep campaign promoting the Back to Sleep message for child care providers in 2003.

This study evaluated the first 2 years of this particular campaign by assessing the number of safe sleep elements that were included in each states' regulations for center and family home child care.

Results showed that since 2003, 60 of the 101 state regulations for both center and family home child care have been revised. Overall, more than one-half of the regulations written since 2003 mandate placing all infants in a non-prone position for sleeping and restrict the use of soft bedding in cribs. These changes are statistically significant. Of the 101 existing state regulations, only 49 require that infants be placed in the non-prone position for sleep. Only 18 have mandatory SIDS risk reduction training for child care providers – licensed and unlicensed.

The study concludes that in the first 2 years of the Healthy Child Care America campaign, there has been success in promoting safe sleep regulations for infants in child care. SIDS risk reduction training and efforts to promote safe sleep regulations in center and family child care must continue.

Summary of Illinois regulations for Licensed Child Care Centers – 2004
- Infants to be placed on side or back for sleep (currently being updated)
- Firm crib mattress required
- Snug fitting mattress required
- No pillow use for infants
- No comforters or quilts in sleeping area
- No smoking in center or in vehicles if child is present

Summary of Illinois regulations for Family Child Care Home – 2003
- Infants to be placed on back for sleep; physician waiver allowed
- Firm crib mattress required
- Snug fitting mattress required
- No pillow use for infants
- No comforters, quilts or bumper pads in sleeping area
- No smoking in home or in vehicles if child is present

Editors note:

SIDS of Illinois was one of the first states to have an active role in reducing/preventing SIDS deaths in Child Care. We have been working with Illinois Child Care Providers for 10 years. We have worked with DCFS Licensing to improve the standards as well as train the licensing representatives who interact with the Child Care Providers who take care of infants. SIDS of Illinois continues to lobby for all Licensed Child Care Centers and Family Child Care Homes to have mandatory annual SIDS risk reduction/Safe Sleep training. Although specific SIDS training is not required in Illinois, it is on the recommended list of continuing education classes.

Since 2000, SIDS of Illinois has trained over 50,000 child care providers. SIDS of Illinois also developed and presented the first Train the Trainer for Child Care Providers at the NAEYC (National Association for the Education of Young Children) Conference in Atlanta, GA in 2000.

SIDS of Illinois also supports any Child Care Providers who have experienced an infant death while in their care.

To read complete study, go to www.sidsillinois.org and click the Research button.

MISSION STATEMENT

Sudden Infant Death Services of Illinois, Inc. is a not-for-profit organization dedicated to the elimination of Sudden Infant Death Syndrome (SIDS) and other infant deaths, serving the State of Illinois since 1972.

VISION STATEMENT

Sudden Infant Death Services of Illinois, Inc. is a statewide not-for-profit organization dedicated to:

- Supporting family members and others who have been touched by the tragedy of Sudden Infant Death Syndrome (SIDS) or other infant death;
- Educating both the public and professionals about bereavement support and infant mortality reduction;
- Creating community awareness on the subject of SIDS and other infant death; and
- Eliminating SIDS and other infant death through the support and implementation of appropriate research.

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